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Quality of Life Following Stroke: The Survivors' Perspective

Janet A. Secrest
University of Tennessee

To the Graduate Council:

I am submitting herewith a dissertation written by Janet A. Secrest entitled "Quality of Life Following Stroke: The Survivors' Perspective." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Sandra P. Thomas, Major Professor

We have read this dissertation and recommend its acceptance:

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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and recommend its acceptance:

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Associate Vice Chancellor and
Dean of the Graduate School

QUALITY OF LIFE FOLLOWING STROKE:

THE SURVIVORS' PERSPECTIVE

A Dissertation

Presented for the

Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Janet A. Secrest

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DEDICATION

To my husband, Alan, and my daughters, Rachel and Marianne

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How can I adequately thank the participants in this study? They generously opened their homes, gave their time, and shared their stories. My life was enriched by them.

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ABSTRACT

Stroke survivors are a common patient population encountered in many areas of nursing practice. Although there are studies on particular aspects of stroke survivors' lives, the information provided is usually decontextualized and compartmentalized so that a sense of the whole person in his/her context is missing. Without a fuller understanding of the stroke survivors' complete experience, it is difficult for nurses to have an empathic understanding of what lies ahead. The purpose of this study was to investigate quality of life as experienced by stroke survivors following rehabilitation. This study was guided by an existential-phenomenological approach. The goal was to arrive at a thematic structure through analysis of in-depth interviews.

The participants were 7 men and 7 women with a mean age of 64. The length of time since stroke ranged from 1 to 23 years, with a mode of 2 years. The participants exhibited a variety of disabilities, including 3 with nonfluent aphasia.

The world of the stroke survivor is grounded in a life of loss and effort from which emerges interrelated themes: in control/out of control; independence-ability/dependence-disability; and connection/disconnection with others. A fundamental aspect of these themes is a sense of continuity while at the same time discontinuity in the experience of self. Other findings included the beneficial effect of the phenomenological interview in facilitating dialogue with those with nonfluent aphasia, and the striking absence of nurses mentioned in the interviews. The thematic structure provides a holistic way of

understanding stroke survivors. The findings have implications for how nurses interact with stroke survivors, the role of nurses in rehabilitation, practice strategies, education and research.

TABLE OF CONTENTS

LIST OF FIGURES

FIGURE **PAGE**

CHAPTER ONE

INTRODUCTION

Stroke is a common cause of disability. In the United States, the annual incidence of stroke is approximately 500,000 (Noll & Roth, 1994), with a prevalence of nearly 3,000,000 (Sacco, 1995). Stroke is more common in older individuals, and, as the population is increasingly aging, the incidence is not likely to decline. Though modest, the trend in survival following a stroke is improving (May, Casper, Croft, & Giles, 1994). Of those who survive stroke, 40% have a mild disability and 40% have a moderate to severe disability (Cifu & Lorish, 1994). Stroke survivors are often the most common patient population in rehabilitation units (Noll & Roth, 1994) where nurses have an essential role in the rehabilitation process. More research is needed, however, to understand ways in which nurses can improve the lives of stroke survivors.

Quality of life (QOL) has frequently been cited by some as the overarching goal of rehabilitation (Anderson, 1982; Crewe, 1980; Kottke, 1982; McCollum, 1988; Symington, 1984;), yet QOL lacks an explicit conceptualization. The promotion of [improved] quality of life is a nursing responsibility stated in the Standards and Scope of Rehabilitation Nursing Practice (Standards) (Association of Rehabilitation Nursing, 1994). Further, the understanding of the concept of QOL is deemed "critical to rehabilitation nursing" (Standards, p. 4). Yet, within the Standards, the only description of QOL is

that it is partially dependent on available community resources thus providing only limited guidance for nurses in fulfulling this responsibility.

Interdisciplinary goal setting is an integral element throughout rehabilitation. It could be inferred, then, that QOL is promoted through goal setting. Goals, by their very nature, are value laden and in rehabilitation high value is placed upon mobility and independence (Caplan, Callahan, & Haas, 1987). According to Lorish, Sandin, Roth & Noll (1994) the focus in rehabilitation units is on impairments resulting from the stroke. Most treatment goals relate to these impairments in an attempt to improve functional outcomes. Thus, quality of life is seemingly equated with improved functional outcomes; this value is reflected in many studies in the rehabilitation literature having improved functional outcomes as their criteria for success. It is questionable, however, whether such outcomes are suitable measures for the patients' quality of life, as suggested in the following three studies.

Doolittle's (1990) ethnography of stroke survivors' recovery found that the participants' view of recovery, which was a return to previously valued (prestroke) activities, differed from the health care providers' view of recovery, which was improved functional abilities. Participants perceived providers to be focused on neurological impairments, and not on the their experience (Doolittle, 1990), thereby suggesting that empathy for the patients' total experience was lacking.

That QOL is more than functional abilities was also found by DeHaan, Limburg, Van Der Meulen and Bassuyt (1993). They correlated stroke severity with disability,

handicap and QOL. Although there were high correlations among stroke severity, disability and handicap, the correlation was low with respect to quality of life. In addition, Ahlsio, Britton, Murray and Theorell (1984) found that even with a significant improvement in activities of daily living (ADL) (an indicator of functional outcomes), the individual's quality of life did not necessarily improve. Thus, while an improved quality of life is a broad goal in rehabilitation, the focus on patients' functional abilities limits the achievement of this goal to activity.

Including the patient and/or the family in goal setting is congruent with rehabilitation philosophy. In fact, collaborative goal setting is one of the nursing standards for rehabilitation (ARN, 1994). In recognizing the "goal oriented" (ARN, 1994, p. 5) nature of rehabilitation, the Standards state that the "nurse helps the client [and/or significant other] develop and prioritize goals" (p. 5). Nurses would naturally assist in this process from their perspective or understanding of what would contribute to the betterment of a stroke survivor's life. The literature is replete, however, with studies documenting differences among nurses', physicians', patients' and significant others' perceptions of phenomena such as end-of-life decisions (e.g., Hare, Pratt & Nelson, 1992; Ouslander, Tymchuk & Rahbar, 1989) and patient needs (e,g, DiIorio, Faherty, & Manteuffel, 1993; Lauer, Murphy & Powers, 1982). It would be reasonable to conclude that similar disparities would exist for stroke survivors, in other words, differences between nurses and stroke survivors views of what contributes to an improved quality of life.

While in rehabilitation, the stroke survivor has too little time to assimilate the experience of this profoundly disruptive event (Doolittle, 1990). Haas (1993), in recognition of this possibility, recommends that providers direct the treatment goals initially when the patient is in this naturally vulnerable position, with the patient assuming a greater role with the passage of time. During hospitalization, at least, health care providers direct the goal setting as shown in two nursing studies of stroke survivors (Davidson & Young, 1986; Doolittle, 1990). Importantly, the health care provider goals were different from and took precedence over those of the patient.

Because improving QOL is at the heart of health care, it has been a much studied topic over the past 30 years using a variety of definitions. Attempts to measure QOL have spawned a virtual cottage industry resulting in numerous instruments. The word "quality" when used with "of life" can be conceptualized as "the nature, kind, or character of something" (Worldbook Dictionary, 1994, p.1703) and/or as "a grade of excellence" (p. 1703). In the literature, the nature of QOL has been generally viewed as having various discrete dimensions (such as health and functioning, psychological, spiritual). Operationalization of the construct in most tools involves quantifying the relevant dimensions to yield scores on the grade of excellence. While many of these instruments provide useful information regarding certain aspects of people's lives, their very nature indicates predetermined, context-free categories. In an extensive analysis of QOL instruments, Gill and Feinstein (1994) concluded that "quality of life can be suitably measured only by determining the opinions of patients and by supplementing (or

replacing) the instruments developed by 'experts'" (p. 619). Similarly, in a philosophical analysis, Hayry (1991) also concluded that the determination of the quality of life "should be left to the competent patients themselves" (p. 97).

In summary, quality of life is an overarching goal for rehabilitation that is promoted through goal setting. Provider treatment goals, which should be contributing to an improved quality of life for the individual, focus on functional outcomes. Improved functional outcomes, however, do not necessarily improve the perception of quality of life for the stroke survivor. In fact, QOL measurements themselves invoke predetermined categories or dimensions which cannot adequately capture what the quality of life is for individual stroke survivors.

While collaborative goal setting is a stated value, stroke survivors may not be able to participate fully in this process. Since their lives have been profoundly disrupted, it is understandable that the health care provider would guide the recovery process initially. But on what do nurses and other providers base their guidance? Studies have provided information on particular aspects of stroke survivors' lives but this information is usually decontextualized and compartmentalized. A sense of the whole person in his/her context is missing. Without a fuller understanding of the stroke survivors' experience, it is difficult for nurses to have an empathic understanding of what lies ahead. Thus, the only guidance that could be provided for stroke survivors would be from the nurses' perspective--which the literature indicates may be inadequate. Understanding the meaning of the stroke in the survivors' own everyday lives should provide nurses with a

more holistic view of the individual in his or her personal contexts.

Purpose

The purpose of this study was to investigate the quality of life as experienced by stroke survivors following rehabilitation. Allowing the survivors, themselves, to tell their story provides a contextualized understanding of what was and is important to them as they reintegrated their lives. These experiences were explored through in-depth interviews conducted along existential phenomenological lines. The specific question asked each participant was as follows: "Please describe specific experiences since your stroke which stand out for you." Through understanding the survivors' complete life experiences, nurses will be able to offer a foundation in which to to develop holistic care for stroke survivors.

Research Perspective

The phenomenon of interest in this study is the quality (or nature) of life as experienced by stroke survivors. Because meaning of life experiences is sought, a qualitative research approach, specifically a phenomenological one, was deemed most appropriate to this task. Qualitative research methods in general provide a basis for exploration and understanding of complex human experiences. These approaches are

philosophically rooted in existential philosophy. From this perspective, the world is seen as evolving and dynamic (Munhall & Boyd, 1993, p. 16) and all experiences are viewed as taking place in relation to the world with which they are inextricably intertwined (Omery, 1988). The "knower and the known are interactive, inseparable" (Streubert & Carpenter, 1995). Context not only shapes the meaning of the experience, but often gives rise to the experience itself. As the world is dynamic, personal reality is also dynamic or changing.

Existential-Phenomenology

Existential-phenomenology is a union of two philosophies which are both concerned with human existence. Existentialism can be traced to the 19th Century works of Kierkegaard, Dostoyevsky and Nietzsche for whom the personal meaning of man's everyday, concrete existence was important. This focus was in contrast to the prevailing search for a systematic understanding of the world (Stewart & Mickmunus, 1973).

Edmund Husserl [1859-1938], a German philosopher, is considered the founder of phenomenology. He was concerned with the deep concerns of people and a "philosophy without presuppositions" (Cohen & Omery, 1994, p. 137). His emphasis was on a rigorous science seeking answers to "what do we know as persons?" (p. 142). This search was through exploring phenomena as they appeared in consciousness.

Existentialism, thus, is a philosophy concerned with questions of human existence, and phenomenology with the methods needed to study existence. Their union, first by Heidegger, then Merleau-Ponty, opened a path for "a rigorous description of

human life as it is lived and reflected upon in all of its first-person concreteness, urgency and ambiguity" (Pollio, et al., in press). This approach seeks to understand a phenomenon in the everyday world, to "investigate people's experiences of life events and the meanings these events have to them" (Becker, 1992, p. 8). The meaning of the stroke survivor's quality of life will emerge from the everyday experiences of the survivors themselves. From an existential-phenomenologic perspective, there are three important aspects of human existence, or consciousness: intentionality, figure/ground, and change and continuity.

Intentionality is understood through the fundamental relatedness of humans and the world. It is a structure of existence which explicates consciousness (or awareness, or action) as always directed toward something. Existence is always contextual and situated: "there is no inner man, man is in the world, and only in the world does he know himself" (Merleau-Ponty, 1962, p. xi). To study stroke survivors' quality of life in isolation from the world, as many studies have, violates this understanding of human existence.

Figure/ground is another important aspect of human experience. Existence, which etymologically means literally "to stand out," emerges as a figure against a ground. Figure/ground is readily seen in reversible pictures of, e.g., the vase and faces, the old woman and the princess. In viewing these types of figures, it becomes obvious that only one facet of the picture is clearly in focus at a time; the other way of viewing the picture becomes the background: one does not exist without the other. So it is with human experience, whatever is figural, is so only against a background. What is ground for one

person, may well be figural for another. What stands out for someone is therefore able to provide significant glimpses into what is meaningful to that person. In studying stroke survivors, figural events and their ground are important in understanding these individuals and their relationship with the world. Most previous studies of stroke survivors have focused on what is figural against the researcher's ground.

Another fundamental aspect of human experience is continuity and change (Pollio, et al., in press). Existence is not a series of discrete events, but dynamic experiences which unfold in a continuous fashion. Integral to this continuity is change. Our field of experience changes, ground becomes figure, figure becomes ground. Yet, continuity of existence in the face of change persists: "certain threads of life--its themes or leitmotifs--tie the present focus to other events and meanings and no event is unconnected from the rest" (Pollio, et al., in press, p. 31). These meanings provide coherence to personal existence. For stroke survivors, the stroke has changed the field of experiences. Aspects of their relationship with the world has changed, yet even the change is one from what once was, and this in itself is a connection with the past. The meaning of the experiences of this change, thus, will emerge from unique connections to the person's past events.

Significance of the Study

Since one responsibility of rehabilitation nursing is to improve the quality of life for disabled individuals (ARN, 1994), it is important to understand what QOL means to

the specific individual. How stroke survivors, themselves, experience their lives should provide a fuller, richer understanding of the impact of the stroke. Such an understanding will be helpful to nurses as they provide guidance to stroke survivors in the reintegration of their lives.

In the ARN Standards (1994) QOL is termed an important concept for rehabilitation nurses to understand, yet this document contains a limited view of quality of life, namely, that it is partially dependent upon available community resources. The results of this study should broaden and clarify the concept of quality of life with regard to stroke survivors as well as provide a basis for nurses to evaluate their own perspectives concerning patient expectations and goals.

While nurses in rehabilitation may find closure with patients upon discharge, there is no closure for the stroke survivor. Because the majority are older adults, future encounters with the health care system are likely. With a stroke prevalence of nearly 3,000,000, nurses in many areas of practice will be providing care to stroke survivors, and it is hoped that the results of the study will be useful in contributing to a holistic view of individuals who have sustained a stroke.

CHAPTER TWO

REVIEW OF THE LITERATURE

The purpose of this study is to investigate QOL as experienced by the stroke survivor following rehabilitation. The research approach will be a phenomenological inquiry. In this chapter, pertinent literature will be reviewed. The review will be organized as follows: epidemiology of stroke; characteristics of stroke survivors; perceptual differences among patients; nurses and significant others; nurses' attitudes toward the elderly and disabled; and perceived quality of life.

Epidemiology of Stroke

Stroke is a common cause of disability. Of the approximately 500,000 new cases per year, 150,000 die, leaving 300,000 with residual disability (Gresham, Duncan & Stason, 1995). The term "stroke" is generic, referring to any disruption of blood supply to localized areas of the brain (Rusin, 1990). Because of the inclusion of differing etiologies, locations, and extent of strokes, as well as comorbidities, risk factors and age of onset, many studies on stroke are difficult to compare. For gathering data on stroke internationally, the World Health Organization Monitoring Trends and Determinants in Cardiovascular Disease (WHO MONICA Project), uses the following definition of

stroke: "rapidly developing signs of focal (or global) disturbance of cerebral function lasting >24 hours (unless interrupted by surgery or death), with no apparant nonvascular cause" (Thorvaldsen, Asplund, Kuulasmaa, Rajakangas & Schroll, 1995, p. 362)

Vascular etiologies of stroke may be classified as ischemic and hemorrhagic. Of the ischemic strokes, thrombotic etiology accounts for 40-50% and embolic, 15-30%. Hemorrhagic strokes (both intracerebral and subarachnoid) account for 5-20% (Noll & Roth, 1994). The 30-day mortality for strokes is highest for hemorrhagic strokes (45-82%), and lowest for ischemic strokes (15%) (Dobkin, 1995).

Mortality has declined, particularly with thrombotic ischemic strokes, which has not been paralleled by a decrease in the incidence (Shahar, et al., 1995). The actual number of stroke survivors is estimated to be 3 million (Sacco, 1995). The U.S. Department of Health and Human Services (1992) has set as its goal for the year 2000 a 34% decrease in stroke mortality from 1987. That is, a reduction from 30 per 100,000 to 20 per 100,000. Thus, a continued increase in the number of stroke survivors can be expected.

Estimates of residual disability in stroke survivors are: 10% no disability, 40% mildly disabled, 40% moderately to severely disabled requiring special services, and 10% requiring long term care (May, et al., 1994). Although only 15% of survivors receive inpatient rehabilitation (Dobkin, 1995) they often account for the most common population in rehabilitation units (Noll & Roth, 1994). Although neurological improvements following a stroke may continue for up to a year, the rate of change after

six months is limited (Gresham, et al., 1995). Improvement in cognitive function is less likely after three months (Gresham, et al., 1995).

The majority of strokes (73%) occur in those 65 years and older, with 43% occurring in those over 74 (Kuhlemeier & Stiens, 1995; Rusin, 1990). Severity of stroke has been significantly related to race (African Americans having increased risk and severity) (Kuhlemeier & Stiens, 1995), less so with gender. Although the differences are small, men are at a slightly higher risk for stroke than women (Sacco, 1995). Most stroke survivors have concomitant risk factors such as hypertension, diabetes, and cardiac disease (Sacco, 1995).

Thus, stroke survivors are generally older individuals with disabilities and with other health risks. A decreasing mortality without a decreasing incidence can be expected to result in greater numbers of stroke survivors. With increasing survival for this group, issues of quality of life become more important.

Psychological Characteristics of Stroke Survivors

The effects of stroke extend beyond the physical limitations. Depression is a very common problem. Its prevalence has been estimated from 33% to 50% (Dromerick & Reding, 1994; Eastwood, Rifat, Nobbs & Rudermann, 1989). In a prospective study of 103 stroke survivors, left hemisphere lesions were correlated more strongly with severity of depression than were right hemisphere lesions (Parikh, Lipsey, Robinson & Price,

1987). Two years poststroke, however, location was no longer correlated. At this time, physical impairment and social functioning were significantly correlated with depression. Although location of the lesion was correlated most highly during the acute phase of a stroke, severity of impairment in activities of daily living, degree of cognitive impairment, the quality of available social supports and age each accounted for between 5 and 10% of the variance in depression scores. Depression was measured by the Hamilton Depression Scale and the Zung Depression Scale. The authors did not report the prevalence of depression at each of the time intervals.

In contrast, R. King (1990) found depression greatest in subjects with right hemisphere strokes one to three years post-stroke. In her sample (n=86), the prevalence of depression was 30%. However, these subjects were screened for language which would have reduced the representativeness of left hemisphere stroke subjects.

Emotional lability, in which the person cries easily in response to discussions of emotionalism or sad situations, is seen in as many of 21% of survivors (Sandin, Cifu & Noll, 1994). Emotional lability, denial and euphoria are more common in right hemisphere lesions. Anger and resentment characterize the narrative of Veith (1997), a physician who survived a stroke.

Although these consequences of stroke may improve or resolve with time, their presence will likely be seen in the rehabilitation unit (Sandin, Cifu & Noll, 1994), influencing the way nurses interact with stroke survivors. There is debate in the literature as to whether these psychological consequences are the result of the lesions

themselves or a reaction to the stroke. Regardless of the etiology, the psychological consequences will nonetheless influence the stroke survivor's experiences, quite likely in ways not appreciated by others.

Perceptions of Patients, Significant Others and Nurses

The idea of patient perception is of great importance to nursing. As Bunting (1988) has succinctly stated, "it is with the client's perception of the world that nurses negotiate, rather than with some objective reality" (p. 174). Research into perceptions and disparity of perceptions among patients, families and health providers has been a focus of several studies. In one set of studies, congruent perceptions between patients and their significant others and health care providers have been investigated with regard to proxy or surrogate decision making with regard to advanced directives.

Using vignettes, primary nurses, social workers, physicians, and significant others (defined as the closest living relative), predicted treatment choices of the patient (n=60) (Ouslander, et al., 1989). The highest rate of agreement was between the relative and patient; lowest was between physician and patient. There were statistically significant differences between all groups, however. The rate of agreement between patient and significant other may be attributable in part to the response rate of the significant others (53%), suggesting that perhaps only the most knowledgable responded.

In another study using vignettes, Hare, et al. (1992), found no statistically significant association between treatment decisions of patients and their surrogates (n=50 pairs). In other words, there was no correlation between what the patients would decide and what their surrogate would decide for them. This was striking since patients chose the person they felt would best represent their wishes. Similarly, Seckler, Meier, Mulvihill & Paris (1991), found a low rate of agreement between elderly patients and their designated proxies (n=57 pairs). This result was found in spite of the patients' high rating of the likelihood that their surrogates would accurately reflect their wishes.

Significant discrepancies in the perception of needs were found between recovering cardiac patients and their spouses (Moser, Dracup & Marsden, 1993). Forty-nine couples participated with 82% of the patients being male. Though both patients and spouses ranked information as the highest need, types of informational needs differed as did many other ratings. In addition, both patients and spouses reported that 40-70% of their needs were unmet by the nursing staff. Further, of the needs ranked most important to the patients and spouses, 70% were unmet. Although many reasons may account for the unmet needs, it is possible that one reason pertains to the nurses' inaccurate perceptions of such needs.

Other studies have examined the relationship between perceptions of nurses and families. Lynn-McHale and Bellinger's (1982) study probed the nurses' perceptual accuracy of needs satisfaction for families of critical care patients. The study group included 92 nurses and 52 family members. Although the authors concluded that the

nurses were "moderately" accurate in their perceptions, their findings suggest otherwise. The nurses' ranking of needs differed substantially from the families'. Ranks 1, 2, and 3 of needs by family members were ranked 10, 11, and 5 respectively by the nurses. The families' top three ranked needs were perceived to being unsatisfied whereas nurses perceived those same needs as being satisfied. There were threats to the validity of this study: the response rate of the nurses was only 53%, and it appeared that nurses and families were not paired. Therefore, nurses would have been responding to generalities about their unit, whereas family members were responding to a specific circumstance.

In another study, perceptions of learning needs of persons with epilepsy were compared among nurses, physicians and patients (DiIorio, et al., 1993). The sample consisted of 59 persons with epilepsy, which represented 100% of the patients approached who met the sample criteria. Their data were compared to data from 83 nurses and 38 physicians, which represented only a 42% and 30% response rate, respectively, from mailed questionnaires. The ranking of needs differed among the groups. There were significant differences between nurses and physicians in four of the five categories, and between patient and physician in one category. No significant differences were found between patient and nurse. The low rate of response by nurses could mean that only those particularly interested in this topic responded, and the respondents were, therefore, more sensitive to these patients' needs than a less selected sample. Again, this was a survey of generalities for nurses and specific circumstance for patients.

When nurses were paired with patients, perceptions of needs for patients with uterine cancer were found to be congruent beween patient and nurse (Lilley, 1987). Fifteen pairs constituted the sample. Educational preparation of the nurse did not affect the results but years of work experience may have played a role in the results--for 75%, work experience was greater than five years. It is possible that the congruence of perceptions could be accounted for on the basis of gender, i.e., female nurses being more able to identify with female patients having a gynecological disorder.

Perceptual accuracy of family needs by intensive care unit (ICU) nurses was found to increase somewhat with more empathetic nurses (Forrester, Murphy, Price, & Monaghan, 1990; Murphy, et al., 1992). When ICU nurses were matched with patient families (n=92 pairs), higher empathy scores in the nurse related to greater perceptual accuracy in 6 of 30 needs. The authors did not specify needs in this study. Empathy was measured with the LaMonica Empathy Construct Rating Scale, which was administered to the nurse only. In this study, some nurses were paired with more than one family. For three of the needs, perception was negatively correlated with the nurses' years of experience. The authors speculated that empathy decreased over time perhaps as a result of a "burnout" process.

In another study of matched pairs (Davies & Peters, 1983), 25 patients and their nurses were surveyed during the first and third week of hospitalization. Greatest congruence was found in the area of physical illness and the least in the stress of the hospital and its routines. Interestingly, and relevant to stroke survivors in rehabilitation,

nurses rated stressors (eg., toileting) as becoming less stressful with time whereas patients viewed them as more stressful with time. Overall, however, nurses rated the stresses higher than the patients. This could relate to Ferrans & Powers' (1985a) observation that in the face of health or other problems, goals and aspirations change. Limitations to this study were that "most" of the nurses were students, and the setting was in Great Britain where cultural factors may play a role.

Perceived quality of life expectations following renal transplantation were compared between patients and nurses (Hathaway, Strong & Ganza, 1990). As with rehabilitation, improvement in QOL is an overarching goal for transplantation. In this study (n=57 patients), patients and nurses responded to a list of hopes and concerns following transplantation. The list was derived from the literature and validated by the researchers. After discharge, one nurse from each shift who had cared for the patients completed the questionnaire. A total of 15 nurses participated. Although nurses and patients saw more positive than negative life changes, the nurses expected significantly greater numbers of positive and negative changes than the patients.

In a follow-up of this study, patients were reinterviewed 16 to 26 months following transplantation to ascertain whose initial expectations were more accurate (Hauser, Williams, Strong, Gonza & Hathaway, 1991). Of the original sample (n=57), 39 were included. The nursing staff's expectations were more accurate. However, while the staff more accurately predicted numbers of changes, patients were more accurate in types of changes. The authors speculated that the nurses were perhaps expecting similar

changes for a majority of patients, rather than focusing on individual patients.

Studies specifically examining congruence between nurses and stroke survivors were not found. However, perceived needs of wives of stroke patients were found to be unmet 66% of the time in one study (Rosenthal, Pituch, Greninger, & Metress, 1993). This small sample (n=14 wives) may not be representative, and unmet needs do not necessarily mean that nurses did not perceive them. The study findings raise questions about what the nurses did perceive as needs and whether the needs perceived were congruent with the wishes or desires of the wives.

In a study of stroke survivors' problems following a course of inpatient rehabilitation (n=29), two questions (of 16) asked: "how did you feel about your rehabilitation program? Were you consulted about what you wanted to learn to do?" (Davidson & Young, 1986, p. 125). Although 15 stated their rehabilitation was "good," 9 stated it was "bad," while 5 were neutral. Lack of consideration of the individual's prestroke lifestyle and "real goals" were cited as the reasons. Some of the comments by the participants included: "did not have enough say about when and where I did things," (p. 126), and "I never did that before the stroke and I certainly don't want to do it now, so why did I have to learn how?" (p. 127). These findings indicate that perceptions of importance of needs were incongruent between provider and patient.

In Doolittle's (1990) ethnography of 13 stroke survivors, perceptions of recovery differed between health care providers and patients. Health care providers saw recovery in terms of physical abilities whereas to patients, resumption of "previously valued

activities" (p. 237) spelled recovery; activities that were important to them "gave them identity" (p. 238). In neither Doolittle's (1990) nor Davidson & Young's (1986) study were health care providers delineated as to discipline.

In summary, perceptual differences occur between a variety of types of patients, significant others and nurses. The study by Hathaway, et al. (1990), suggests that nurses generalize about patients rather than focus on individual situations. Transplantation, however, involves quite a different patient population, and offers a different future than that envisioned by stroke survivors. Two studies (Davidson & Young, 1986; and Doolitle, 1990) suggest that the perceptual differences relate to differing goals, however, nurses were not specifically delineated in the group of health care providers. It could be assumed that perceptual differences would be present although the question arises as to how they are different. While all of these studies indicate differences in how health care providers and patients view care, none provides insight into patient experiences.

Attitudes Toward the Elderly and Disabled

Whereas perception is an awareness, attitude reflects a more reflected appraisal or feeling about a given situation or cause. Attitudes arise from one's perception and also shape future perceptions. Since the majority of stroke survivors are elderly, attitudes about the elderly have relevance to the care they may receive.

Attitudes of nurses toward the elderly were the subject of Slevin's (1991) study. Student nurses' (n=85) attitudes were compared with those of graduate nurses' (n=86), using the Attitudes Toward the Elderly Instrument. Interestingly, the attitudes of the student nurses were more positive than the graduate nurses who were all employed in geriatric settings. Since the graduate nurses were older than the students, age may have played a role, as could have education, experience, and work setting. This was a British study, for which attitudes have been anecdotally reported to be different.

Attitudes toward those with disabilities are influenced by knowledge and perceptions. Inaccurate perceptions of disabilities were found among a large group (n=907) of students in the health professions, among which nursing was included (Westbrook, Adamson & Westbrook, 1988). Students tended to exaggerate the number of institutionalized disabled, the amount of community assistance required, and the degree of social isolation. The subjects greatly underestimated the employment status of the disabled.

Studies of health professionals' attitudes toward the disabled suggest that contact or association with the disabled increases positive attitudes. Benham (1988), and Elston and Snow (1986) found generally positive attitudes in occupational therapists, rehabilitation counsellors and other nonnursing personnel in rehabilitation settings.

Student nurses (n=263) scored significantly more positively in attitudes toward the disabled following a one day conference on care of the disabled (Lindgren & Oermann, 1993). The pretest and posttest were administered on the same day so that longer term

effects are not known. Additionally, those with previous work experience with the disabled scored the highest. These results supported a previous study in which a specific educational program on stroke improved the attitudes of nurses in general hospital units (Hamrin, 1982).

Gibbon (1991) demonstrated what he labeled ambivalent attitudes toward stroke survivors in a general hospital setting (n=84). The subjects, who were staff nurses, scored in a median range of the instrument developed by Hamrin (1982). The author does not give sample questions but stated that they were negatively and positively worded with a Likert scale response. The median range may mean indifference or neutral feelings rather than ambivalence. His results did indicate that the more positively nurses viewed rehabilitation, the more interesting the nurse regarded stroke patients.

The majority of stroke survivors are elderly. Attitudes and perception are inextricably intertwined, and influence nurse-patient interactions. Attitudes toward the elderly and/or disabled which are stereotypical or negative, therefore, should influence perceptions about stroke survivors and their quality of life, and therefore, influence the guidance nurses provide in the goal setting process.

Perceived Quality of Life

Development and Application of the Concept

The study of quality of life has mushroomed in the last few decades. Government studies in the past have been based on objective criteria such as economic status. Conceptualization of QOL has increasingly focused on subjective evaluations. Alexander and Willems (1981) attribute this shift in emphasis to social and political changes in the 1960s. Quality of life has been generally viewed as multidimensional in nature. In a concept analysis of QOL in the literature, dimensions of the concept were found to be health and functioning, socioeconomic, psychological/spiritual and family (Oleson, 1990). The development of QOL measures has been the impetus for the following set of studies.

Satisfaction with life is one dimension with much empirical support. It is distinguished from happiness, which Campbell (1976) considered a more unstable, mood-based trait. Neugarten, Havighurst and Tobin (1961) conducted extensive interviews with a random sample of 177 men and women aged 50 to 90 to derive components of life satisfaction in old age. Through a series of interviews over several years, the themes which emerged were: zest, resolution and fortitude, congruence between desired and achieved goals, positive self concept, and mood tone. From this inductive work, an instrument was developed called the Life Satisfaction Rating Scales. Of significance, was the stated exclusion of the chronically ill and physically impaired from the sample and, thus, health did not emerge in the themes.

Dimensions of health, such as illness and disability, however, may not be considered as prominently in assessments of quality of life unless threatened. This was the case in Cantril's (1965) ambitious study of aspirations and satisfactions in life. Using an inductive approach, he gathered information on what constituted the best and worst possible life from the perspective of "an individual's own reality world" (Cantril, 1965, p. 25). For a random sample of 1500 Americans, the best possible life included favorable economic situations, which comprised the top category, with health and family ranking second and third. In looking at fears for the worst possible life, however, health ranked first, with economic situation and family following.

Satisfaction and sense of well-being are often linked. In another large-scale prospective design, Campbell, Converse and Rogers (1976) identified 12 "domains of life": self, standard of living, family life, marriage, friendships, work, neighborhood, residence, nation, housing, education, and health. The first of these six domains had the highest correlation with satisfaction with life in general. These categories were predetermined by the researchers and were "naturally, somewhat arbitrary" (Campbell, et al., 1976, p. 62). Older subjects had greater satisfaction, but less happiness than younger subjects, except that satisfaction with health declined with age. Married subjects had higher levels of satisfaction, with family life and marriage ranking first and second in importance. Health was ranked eighth.

In another attempt to ascertain the dimensions of quality of life, Flanagan (1978) used a critical incident technique. The 65,000 incidents arose from a variety of questions,

including one about something satisfying, and another regarding something the person had wanted, but was thwarted in its attainment. Fifteen themes emerged, of which health was one. Flanagan (1978) does not report, however, which themes arose from which question. The 15 themes were then linked to a 5-point Likert scale and administered to a random sample of 3,000 healthy male and female 30-, 50- and 70-year olds (6 groups). Health was rated as important or very important for 95-98% for the six groups. Significantly, however, when correlated with a report of overall quality of life, the category "material comforts" was highest. This was consistent with Cantril's (1965) findings. Significantly, the sample again was drawn from a "healthy" population.

When health has been affected by illness and/or disability, one might expect the measure of QOL to change. This has not been the case, however. The instrument derived from Flanagan's (1978) study (the QOL Scale) was used to study 227 adults, conveniently chosen, with a variety of chronic illnesses (Burckhardt, Woods, Schulz and Ziebarth, 1989). The responses generated from subjects with four chronic illnesses (diabetes mellitus, ostomy secondary to colon cancer or colitis, osteoarthritis and rheumatoid arthritis) were similar to Flanagan's (1978) with broader importance attached to independence. In Flanagan's (1978) study, independence related to recreation and work whereas in this study, independence included ADL and not wanting to depend on others.

A high measured quality of life is not necessarily incompatible with chronic illness. QOL has been studied in those receiving transplants. Hathaway, Hartwig, Winsett, and Gaber (1992) found QOL improved in 48 kidney transplant subjects over a

one year period. The scores on the Sickness Impact Profile, the Quality of Life Index, the Adult Self Image Scale and the General QOL Scale all demonstrated positive improvements.

Quality of life was also studied in two groups of liver transplant subjects, one short term (less than 24 months, n=17) and the other long term (more than 24 months, n=18) survivors (Hicks, Larson, & Ferrans, 1992). The Ferrans and Powers' Quality of Life Index and the Sickness Impact Profile were used to assess not only quality of life but also associations among quality of life and health-related variables. In both groups, quality of life was high despite significantly greater health-related functional impairments of the long term survivor group. Similarly, in a group of hemodialysis subjects, quality of life was high, though lower than in a healthy population (Ferrans & Powers, 1992).

If the rating of the dimensions of quality of life are similar in healthy populations and in those with illness, and if health is an important dimension, what would account for the similarities in quality of life? One answer has been attributed to changes in the importance of the dimensions. Calman's (1984) view of a good QOL is "when the hopes of an individual are matched and fulfilled by experience" (p. 124). He goes on to add that the gap between hopes and experience can be lessened "by making expectations more realistic or by encouraging the individual to grow in other ways" (p. 127). Calman's (1984) conceptualization has some empirical support. Ferrans and Powers (1985b), for example, found in a group of hemodialysis subjects that life goals and aspirations changed in that independence became less valued, family relationships more highly valued, and

goals changed to focus on living for today. This supported an earlier study in which hemodialysis patients shifted goals (Goldberg, 1974). Patients were satisfied with their altered goals.

This shift in goals or aspirations is not limited to those with illness. Changes in the importance of the measured dimensions of quality of life are seen across the lifespan. Campbell, Converse & Rodgers (1976) found satisfaction with life was higher with increased age while happiness was higher with younger subjects. In addition health assumed greater importance with age.

Palmore and Kivett (1977) found that life satisfaction over a 4-year period in subjects aged 46 to 70 years (n=378) was significantly related to initial self reports of health and, though to a lesser extent, sexual enjoyment and social activity. For this group, however, life satisfaction remained relatively stable. Thus, the individual's perception of health related to their satisfaction.

Another important reason there is little difference between ill and well samples could be that the instruments used simply do not adequately capture the meaning of QOL. Hathaway (1995) found qualitative differences in the experiences of transplant recipients for whom differences were not previously found when using quantitative methodology. Several previous studies had not found significant differences between kidney-alone and kidney-pancreas transplants, which was at odds with clinicians' experiences. When interviewed with open-ended questions, a group of participants who had both a kidney-alone transplant as well as a later kidney-pancreas transplant, new

themes emerged. Following a kidney-alone transplant, themes of energy, choices and being alive predominated. When these same participants subsequently became kidney-pancreas recipients, reports of normalcy, freedom and control emerged. Though the sample was small (n=4), it does raise questions of the ability of QOL instruments to meaningfully measure the concept.

Following an extensive review of QOL instruments, Gill & Feinstein (1995) concluded that because "QOL is a uniquely personal perception" (p. 619) it is best approached through the "opinions of patients" (p. 619). They caution that regardless how elegant an instrument and study may be, unless the patient's perspective is considered, there will be "unsatisfactory face validity" (p. 624). Prior to this review, Hayry (1991) reached the same conclusion through a philosophical analysis of quality of life saying that "definitions [of quality of life] should be left to the competent patients themselves" (p. 97). While measurement of QOL to date has provided information on discrete areas of life, it has not provided understanding of the experience of life nor a holistic view of individuals.

Quality of Life in Stroke Surivors

Stroke affects health in many ways which are different from the chronic illnesses mentioned in the transplant and dialysis studies. Its sudden onset, usually in an older age group, strikes at the very essence of the individual's personhood. To compound this, the threat of recurrence looms. The literature is replete with outcome studies on stroke rehabilitation which assess functional abilities. While functional abilities are important to

QOL, they are not the only contribution and, thus, can only partly capture perceived QOL; this conclusion is highlighted in the following three studies.

DeHaan, et al. (1993), correlated well known stroke severity scales which measure impairment (NIH scale, Canadian Neurological Scale, the Matthew scale, and the Scandinavian Stroke Scale) with disability (Barthel Index), handicap (Rankin Score), and quality of life (Sickness Impact Profile). The following definitions were used (WHO, 1980): stroke severity is the degree of impairment from the stroke; disability, the degree of functional loss; and handicap, which is the extent to which the individual feels socially disadvantaged. The sample of 87 stroke survivors (mean age=71.9 $\pm$ 11.52 years) were six months post-stroke. Present living arrangements were not mentioned. Although there were high correlations among stroke severity, disability and handicap the correlation was low with quality of life.

Ahlsio, Britton, Murray and Theorell (1984) found that even with a significant improvement in ADLs, an indicator of functional outcome, the individual's QOL did not necessarily improve. In this study, 96 consecutive stroke survivors (mean age=71, no SD given) were followed over a 2-year period. The researchers used a visual analogue scale to measure perceived changes in QOL.

Similarly, in a group of 27 younger stroke survivors (mean age=48 years; range 17-61 years), "good recovery in terms of discharge from the hospital, ADL, return to work" (Niemi, Laadsonen, Kotila & Waltimo, 1988, p. 1105), did not restore the individual's QOL. Deterioration in QOL was correlated most strongly with hemispheral localization

(versus brainstem or no localizable lesion), paresis, coordination disturbances and subjective tendency to depression. The latter accounted for the greatest variance, however, it was not clear how this was measured.

These three studies (DeHaan, et al., 1993; Ahlso, et al., 1984; and Niemi, et al., 1988) all were conducted on European subjects. Perception of quality of life may differ culturally between Americans and Europeans. Cultural differences in perceived QOL and aspirations were found in Cantril's (1965) results. A report by a disabled American doctoral student studying in England highlighted attitudinal differences between England and the United States (Peace, 1988). The author found disabled individuals referred to as "invalids" who were rarely seen in public unless accompanied by a caretaker. This limited view of post-disability life would seem to significantly alter one's perception of QOL, and thus, English study results may not be relevant to American subjects

Using the Ferrans and Powers Quality of Life Index, R. King (1990) found perception of a high quality of life for a group of American stroke survivors one to three years post-stroke (n=86). Functional status was a weak predictor of quality of life. Depression, present in 30% of the subjects, was the strongest predictor of QOL, i.e., the less depression, the higher the quality of life. Age and socioeconomic status were not significantly related to QOL; however, age was significantly related to functional status (a weak predictor) and socioeconomic status was significantly related to depression (a strong predictor). There were a significantly greater number of subjects with right hemisphere strokes who were depressed. Although there were comparable right and left

hemisphere stroke subjects, they had been screened for language abilities, which would presumably have reduced the representation of the field of those with left hemisphere lesions. The author did not report how many subjects were screened before the sample was obtained. Additionally, screening was done for cognitive abilities, and all subjects were living at home so this would be a limited representation of stroke survivors. As with previous studies, however, functional status was not a strong predictor of QOL.

Life satisfaction and ADL one year post-stroke were significantly worse for subjects with right hemisphere strokes in a Scandinavian study (n=346) (Johansson, Jadback, Norrving, & Widner, 1992). Life satisfaction was assessed at 6 and again at 12 months poststroke with an instrument (Nottingham Health Profile) consisting of questions on mobility, energy, pain, emotional reactions, sleep and social isolation. The authors related the worse outcomes for the right hemisphere stroke survivors to diminished spatial awareness and neglect syndrome (inattentiveness or ignoring of one side of the body and/or environment); however, depression was not assessed.

Focus on the everyday experiences of stroke survivors has received limited attention in the literature despite a recognized need (Doolittle, 1988; Adkins, 1993). Davidson and Young (1986) elicited information from 29 participants through specific questions (e.g., "were you consulted about what you wanted to learn to do?" [p. 125]). With regard to QOL, an analogue scale of 1-10 was used to compare pre- and post-stroke QOL. The younger stroke survivors experienced a greater decrease in QOL. Importantly, the routines learned in the rehabilitation hospital changed when stroke survivors returned

home.

Doolittle (1990), while investigating the experiences of stroke survivors, focused on the progression of bodily recovery and practical knowledge gained. Participants in this study experienced different phases beginning with "the shock of sudden immobility" (p. 100). The stroke survivors and health care providers approached recovery differently. Health care providers looked at recovery in terms of functional abilities whereas stroke survivors defined it as progress toward resuming meaningful prestroke activities. Interestingly, those with less functional impairment often had the most difficulty adapting to the changes. This study was conducted over a six month period, beginning within days of the stroke event.

Robinson-Smith and Mahoney (1995) conducted interviews with seven stroke survivors and their spouses in order to understand coping and marital equilibrium. The participants were between 6 and 12 months poststroke. Using content analysis, the researchers found four themes: experiencing physical changes, feeling down and worrying about the future, being restricted and adjusting to limits, and seeking a new balance in the marriage. While this study extends Doolittle's time frame, the inclusion of spouses in the interviews provides a couple perspective and may have imposed limitations on the stroke survivor. These studies provide valuable insights into aspects of the experience of stroke survival and provide a basis for this study. What is not known is how the stroke survivor experiences the quality of life after further neurological recovery is no longer expected.

Summary

Stroke survivors are a common patient population, the majority of whom are elderly. The effects of stroke are varied and include psychological consequences. Most neurological recovery occurs within the first six months following the stroke. Perceptual differences between patients and nurses, families and nurses, and patients and families have been well documented in the literature. Nurses' attitudes toward the elderly and the disabled are not necessarily positive. Since stroke survivors are usually elderly and disabled, these attitudes may negatively affect the nurses' perception of the stroke survivor's QOL. Two nursing studies of stroke survivors revealed perceptual differences between them and their health care providers with regard to goals and recovery.

Quality of life has been viewed by researchers as measurable, multidimensional aspects of life. In previous decades, dimensions of QOL have been derived from studies of healthy populations. Instruments based on these dimensions have not found large differences between healthy and ill samples, despite "health" being one of the categories. While QOL instruments may provide important information, the experience and meaning of the individual's experience of quality of life cannot be measured. The literature has focused on grade of excellence for quality of life, not on the nature of the experience. To understand the illness trajectory of stroke survivors in order to provide nurses with a deeper understanding of what the quality or nature of life is following a stroke, the survivors themselves must tell their story. The purpose of this study, then, was to

investigate the quality of life as experienced by the stroke survivor, using a qualitative, dialogic approach.

CHAPTER THREE

METHODOLOGY

This was concerned with investigating the quality of life as experienced by the stroke survivor. Using an existential-phenomenological approach, "primacy is placed on the perspective of the experiencing individual" (Thompson, Locander & Pollio, 1990, p. 347). The goal of the present study , therefore, was to arrive at thematic description of the phenomenon, which is the quality or nature of life following a stroke.

Participants

Sample selection in phenomenological approaches is purposive. Participants must not only be knowledgable about the phenomenon, but also must be those "who [are] able to reflect and provide detailed experiential information about the phenomenon" (Morse, 1991, p. 131). Participants were recruited through personal contacts and "snowballing," in which participants referred others. The criteria for inclusion in the study were that the participant:

1. was willing and able to articulate the experience
2. had been hospitalized for a primary diagnosis of stroke

3. had completed inpatient rehabilitation

4. was at least 6 months from time of stoke.

The sample size must be small enough to allow for a "deep, case-oriented analysis" (Sandelowski, 1995, p. 183), but large enough to reveal "a new and richly textured understanding of experience" (p. 183). The sample size for this study was 14 (7 men and 7 women).

Protection of Human Subjects

Prior to contacting potential participants, approval was first obtained through the College of Nursing's Human Subjects Review Committee, and then by the University of Tennessee Institutional Review Board (see Appendix A). Written and oral informed consent to interview and tape the interview were obtained from the participants prior to the interview (see Appendix B). Participants were informed that they could stop the interview at any time and withdraw, without penalty, their consent to have the interview used in the study. A copy of the consent was given to each participant. Each tape and transcript was identified by number only; researcher chosen pseudonyms were added for the final report. The transcriber and members of the research group signed confidentiality statements (see Appendix C). The signed informed consents are kept in a locked file in the researcher's office separate from the tapes and transcriptions.

The risk of the interview to the participant was anticipated to be emotional, as issues sensitive to the person could arise for which the researcher would offer supportive feedback and debriefing. The researcher is a neuroscience nurse with 23 years of nursing experience, 10 with neurologically impaired individuals. Thus, she was well prepared to intervene with any emotional distress produced by the interview. Some phenomenological interviewers have noted that although the interview may elicit emotional responses, the participants nevertheless found the experience to be beneficial (Hutchinson, Wilson, & Wilson, 1994). While the interview did prove to be emotional for several participants, they seemed pleased to have been able to participate and thanked the researcher. One participant expressed some feelings of hopelessness and helplessness, though he denied suicidal thoughts. He was under the supervision of a psychiatrist and was on antidepressants. He was advised to recontact his psychiatrist, which, in a subsequent call, he indicated he had.

Procedure

The researcher's bracketing interview was conducted by a member of the University of Tennessee phenomenological research group. The tape recorded interview was transcribed verbatim and analyzed in the group. Following approval from University of Tennessee Institutional Review Board, potential participants meeting the criteria were recruited through personal contacts. None of the participants was known to the

researcher prior to the interview. Participants were contacted by telephone; all but one person contacted agreed to participate. Interviews lasted between one and two hours. For the first two participants, demographic data (see Appendix D) were obtained prior to the interview. On asking demographic questions, participants began describing experiences amd in order to capture participants' unreflected descriptions, demographic data were collected following the interview for subsequent participants. After each interview, the participants had the opportunity to ask questions and discuss the interview.

All taped interviews were transcribed verbatim. The researcher listened to each tape and read the transcripts on several occasions, first listening/reading for a sense of the whole, then for part-to-whole meanings. Each transcript was summarized using direct quotes. Three of these with their respective transcripts each were read by a different person to verify fair representation of the original transcript. During this process, interpretive notes were made on the transcripts.

The first three interviews were analyzed within the research group, which also provided assistance to the researcher with interview techniques. A fourth interview was selected for group presentation because of the participant's aphasia, a variation from usual phenomenological interviews. In addition, several of the transcript summaries with initial themes were presented to the group. The thematic structure was partially developed in the group and a diagram presented to determine comprehensibility. This was then taken to participants to ascertain consistency with their experience.

The Interview

The purpose of the interview was to uncover detailed, unreflected first person descriptions of the phenomenon through a dynamic, dialogic process. The primary focus of the interview is on the phenomenon itself, not the person (Pollio, Henley, & Thompson, in press). Through the interview, "a field of purely present experience" (Ihde, 1986, p. 35) is sought which describes rather than explains.

Kvale (1996) separates the words inter and view to emphasize the duality of the encounter; inter also emphasizes the connection between the researcher and participant. The participant is not considered a subject, but rather a co-participant or co-researcher. The interviewer seeks a full uninterpreted description. As the phenomenon is explored, the meaning of the experience for the individual continues to evolve and the participant may find new insights. For example, one participant repeated several times, "I just now thought of this."

The interview itself was based upon one question from which the dialogue flowed. All subsequent questions were asked to seek clarification, validation or elaboration of what the participant described. Participants were interviewed at locations of their choice--twelve at home, two in the researcher's office. Each interview began with the question: "Please describe specific experiences since your stroke which stand out for you." Specific experiences were requested in order to keep the focus on the person's lifeworld without interpretation. Existence literally means "to stand out"; what stands out for stroke survivors is their existence.

Bracketing

In phenomenology the researcher must be open and present to a full range of experience. To accomplish this, "it is essential that ordinary belief and taken-for granted theory be suspended so far as to allow glimpses of what will later be seen more fully" (Ihde, 1986, p. 34). In phenomenology, this process is called bracketing. Pollio, et al. (in press) traces the initial view of bracketing as a negation or suspension of belief to Husserl's assumption that "the rules of consciousness transcend situations" (p. 71). Such an approach decontextualizes consciousness and seems antithetical to the assumption of intentionality. Pollio, et al. (in press), thus offers an alternative view of bracketing as "an attempt to identify and correct interpretations in which the phenomenological perspective has been co-opted by incompatible suppositions" (p. 71-72). Bracketing was not a single event, but occurred throughout the research process, and included a bracketing interview of the researcher, selection of the participant interview question and critical interpretation by a research group.

Prior to conducting interviews, the researcher was interviewed by a member of the interpretive research group on experiences with stroke survivors. The interview was transcribed verbatim and analyzed within a group familiar with dialogic interpretation. Themes similar to those of the participants emerged. In the bracketing interview, however, the life of the stroke survivor was seen in negative, bleak terms. For example, while the stroke survivors experienced being in control/out of control, the researcher saw only out of control.

The interview question provides the participant with the boundaries of the dialogue. It is important, therefore, that it is asked in a way that encourages a full experiential description of the phenomenon. To achieve this purpose, the research group provided a forum for question development which facilitated insight into the many ways a question could be interpreted by participants.

Bracketing continued as transcripts were analyzed within the group. Pollio, et al. (in press), emphasize that the purpose of the research group is not consensus building, but rather is critical in nature, testing the adequacy and veracity of competing interpretations. As members offered interpretations, it would be incumbent upon that person to point to the specific passage in the text of the interview which supported the interpretation. In summaries of the transcripts and in the final thematic structure, the words of the participants were used to support all interpretations.

Analysis of Data

Pollio's (Pollio, et al., 1997; Thompson, Locander & Pollio, 1989) interpretive framework was used in this study (figure 1). The purpose of the interpretation is to recognize patterns or themes in the experience and to describe their interrelationships in a thematic structure. It is important to distinguish between infer and interpret in the context of the analysis. To infer means to bring in; the inference is not in the text, but is brought in, e.g., from a theory, to render an understanding. Interpret, on the other hand,

Steps for Doing a Phenomenological Research Project

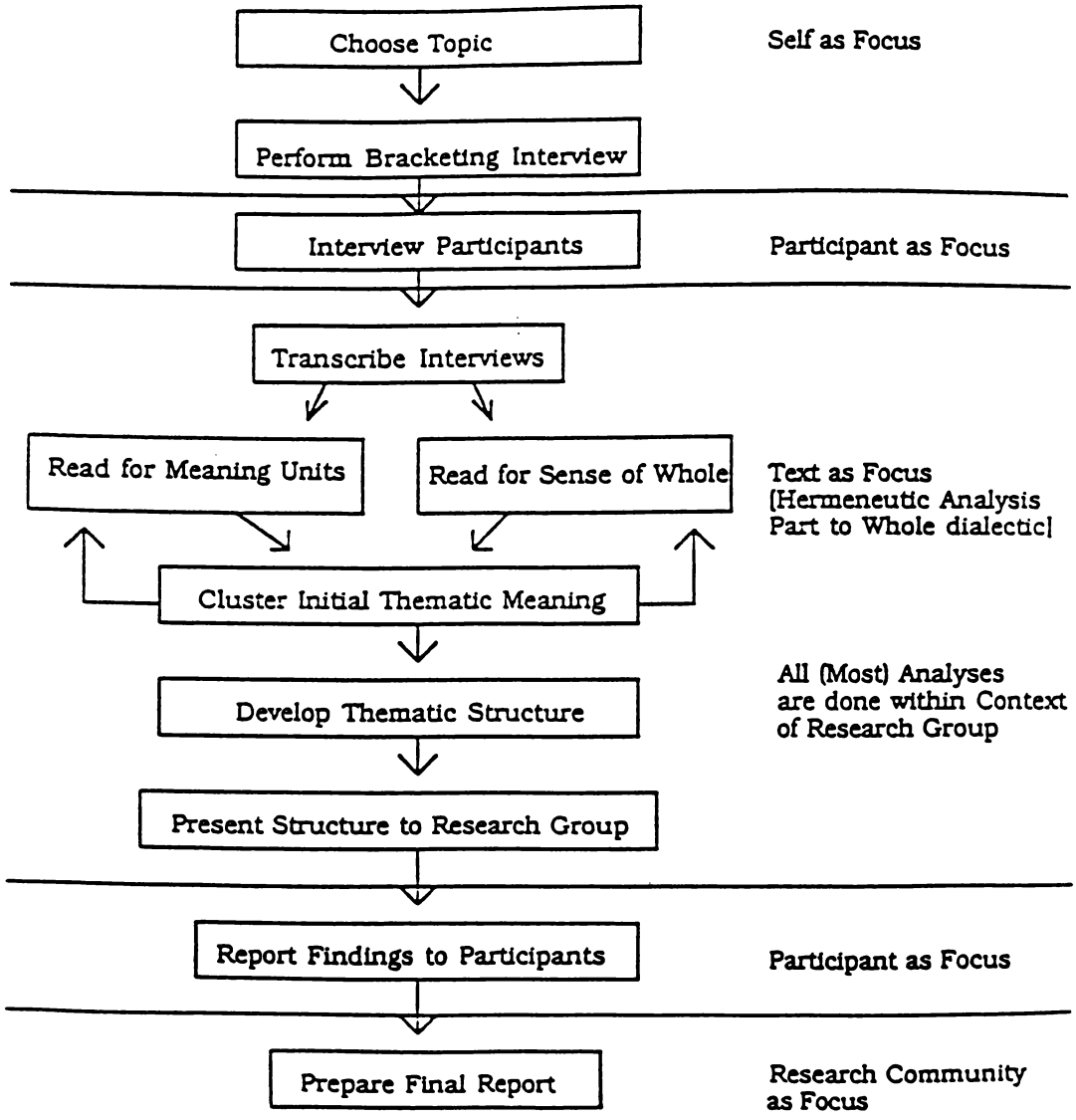

Figure 1. Steps for Doing a Phenomenological Research Project (Pollio, et al., in press)

means to carry between; the interpretation brings alive an understanding directly from the text (interview). In existential-phenomenology, the purpose is to describe, not explain, thus, analysis is an interpretation of the experience which is represented in the thematic structure. The themes that emerged are directly supported in the words of the participants.

Hermeneutic Circle

The hermeneutic circle is a way of interpreting texts through a part-to-whole process (Thompson, et al., 1989). This approach offers a contextual basis for all interpretation through an understanding of the relation between a passage (part) of an individual text and the entire (whole) text, and individual texts (part) in relation the all of the texts (whole); the "wholes" are in turn understood in relation to the parts. Although the process is one of a back and forth movement between part and whole, the understanding is more a spiral. With each return to the part or whole, a deeper understanding is attained.

The research group is an important aspect in implementing the hermeneutic circle. Analysis begins with an individual transcript which is read aloud within the group. Any group member is free to interrupt the reading to discuss, question or offer an interpretation of a passage. Discrete passages are understood in the context of the whole transcript and vice versa. Each transcript is understood in this part-to-whole fashion, though not all interpretations are done within the group setting. Understanding of individual transcripts then proceeds to understanding across transcripts, again in a part-

to-whole spiral. Through immersion in the data, patterns and themes emerge within and across transcripts. The themes "must emerge from respondent descriptions, rather than from abstract or theoretical conjectures" (Thompson, et al, 1989, p. 141); the themes represent the participants' perspective and are supported by the participants' words.

Validity and Reliability

The word validity comes from Latin meaning "to be strong." In quantitative research designs, this is meant to reflect the accuracy of the measure or the findings, as predicted by the researcher. In this design, validity refers to the strength of truthfulness of the findings, which are not predicted, and which are from the perspective of the participant. Credibility is perhaps a more appropriate word in this context (Sandelowski, 1986). Credibility can be assessed by asking those who have experienced the phenomenon whether the thematic structure is consistent with their experience. In this study, participants readily recognized their experience when shown the structure.

Since the purpose is to understand the participants' experience, a threat to the credibility of the findings is an overlay of the researcher's perspective. This threat is mitigated somewhat by the bracketing interview and its analysis, by the development of the interview question within the interpretive group, and by the ongoing critique and dialogue within the interpretive group. Using the actual words of the participants to support all interpretations also furthers the credibility of the findings.

Reliability refers to consistency and stability of findings, i.e., that if repeated, the findings would be duplicated. This concept violates assumptions of the

phenomenological method, in that the dialogic mode of data collection itself changes the participant's experience of the phenomenon. Auditability has been suggested a more appropriate criterion for evaluation (Sandelowski, 1986). Auditability was achieved through analysis of selected transcripts within the interpretive group as well as group response to the final thematic structure. While exactly the same results would not necessarily be expected from a repeated study of even these same participants, there is the expectation that others would arrive at a similar structure given these data. Therefore, in this study, auditability is enhanced through the use of participant quotes to support all themes.

Summary

An existential-phenomenological methodology was employed to seek first person descriptions of the world of stroke survivors. In-depth phenomenological interviews were conducted with 14 participants whose confidentiality was maintained throughout the study. Selected transcripts were analyzed within an interpretive group in a part-to-whole dialectic called a hermeneutic circle. Credibility of findings was sought by making figural potentially restrictive researcher perspectives. This concern was addressed by the bracketing interview, group assistance with the development of the interview question, and critical group analysis of transcripts. Use of participants' words to support themes and obtaining participant responses to the thematic structure further enhances credibility.

CHAPTER FOUR

RESULTS

The purpose of this study was to investigate quality of life as experienced by stroke survivors following rehabilitation. A thematic structure of the experience was sought through a phenomenological inquiry. Fourteen stroke survivors were asked the question: "Please describe specific experiences that stand out for you since your stroke." Subsequent questions depended upon the interview, and were asked only for clarification. (See Appendix E for a prototype of an interview.)

In this chapter, the demographic characteristics of the participants will be presented, followed by a description of the thematic structure attained. Thematic elements will then be described individually through excerpts from the interview transcripts.

Demographic Characteristics

There were 7 male and 7 female Caucasian participants ranging in age from 40 to 93 (median 67). The length of time since the stroke ranged from 9 months to 23 years (median and mode 2 years). The majority of participants suffered a left hemisphere stroke (10); one reported a right hemisphere stroke and three participants' strokes

occurred in either the brainstem or cerebellum. One participant reported a stroke from an arteriovenous malformation (Rob), while the rest reported ischemic strokes.

All lived at home, 10 with spouses and 4 alone. The four who lived alone, however, had at least one significant other with whom the participant had daily or near daily contact. Although most had achieved independence in activities of daily living, all experienced neurological deficits at the time of the interview, with various combinations of aphasia, memory loss, hemiparesis/plegia, and sensory changes. Eight experienced some degree of aphasia; three had marked impairment (Luke, Bob, Calvin), however, all were able to participate in an interview.

Those with marked aphasia utilized different strategies when conveying experiences. All made extensive use of gestures and repeated attempts to say words which were initially not understood by the researcher. Luke, in talking about his neighborhood and an assisted living center under construction, walked fingers over a coffee table to represent people, places and relationships. He did this throughout the interview to indicate the same concepts which became readily understood by the researcher. Calvin was able to write some words he was unable to say. These interviews required frequent clarification and validation by the researcher.

The Thematic Structure

The world of a person who has had a stroke is experienced as one of loss and effort. Loss and effort appear most directly to the stroke survivor in terms of connection/disconnection with others, independence-ability/dependence-disability, and being in control/out of control in certain aspects of life. All of this reveals itself in a fundamental way through which the stroke survivor experiences a continuity of self while at the same time experiencing a discontinuity of self. The person is both the same and not the same as before the stroke.

The grounds for the thematic structure, then, are the inseparable themes of loss and effort. From the loss/effort ground emerges a 3-dimensional, pyramid-like structure with the base formed by the interrelated themes of 1) connection or disconnection with others, 2) independence-ability or dependence-disability, and 3) in control or out of control. Loss/effort become progressively more defined in the structure through the various themes, all of which reveal the essence of the experience, which is, who I am is continuous with who I was before the stroke but, paradoxically, discontinuous with who I was. The continuity and discontinuity in the experience of self then forms the peak of the structure (Figure 2). The ground of loss/effort is experienced figurally when it manifests in terms of independence or dependence, connection or disconnection from others, and in being in or out of control. These themes were described as percolating back down again to loss/effort; they also served to define the overall thematic meaning of the

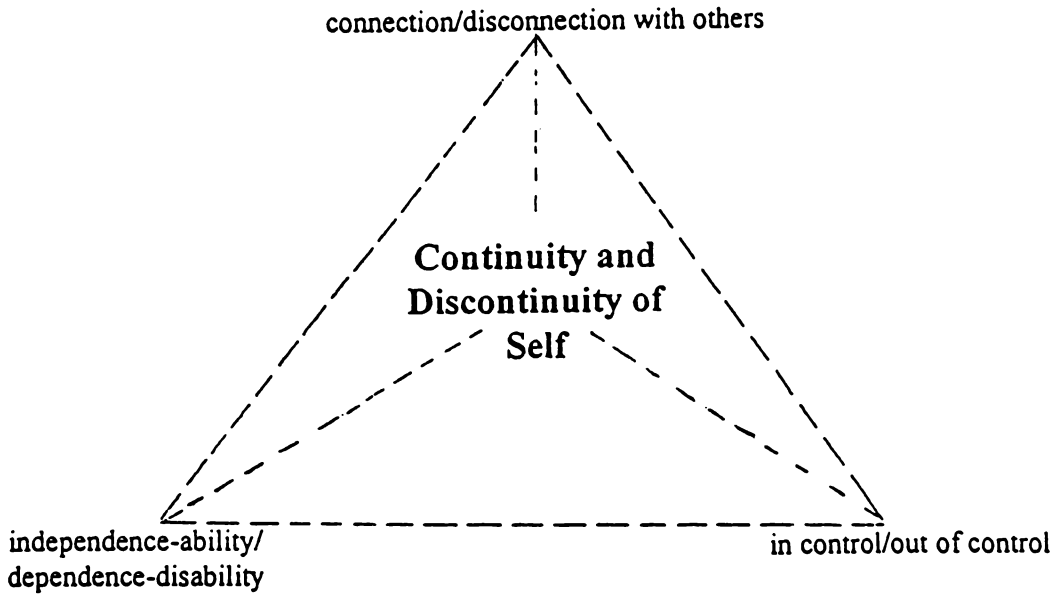

Figure 2. Thematic Structure: Quality of life following stroke

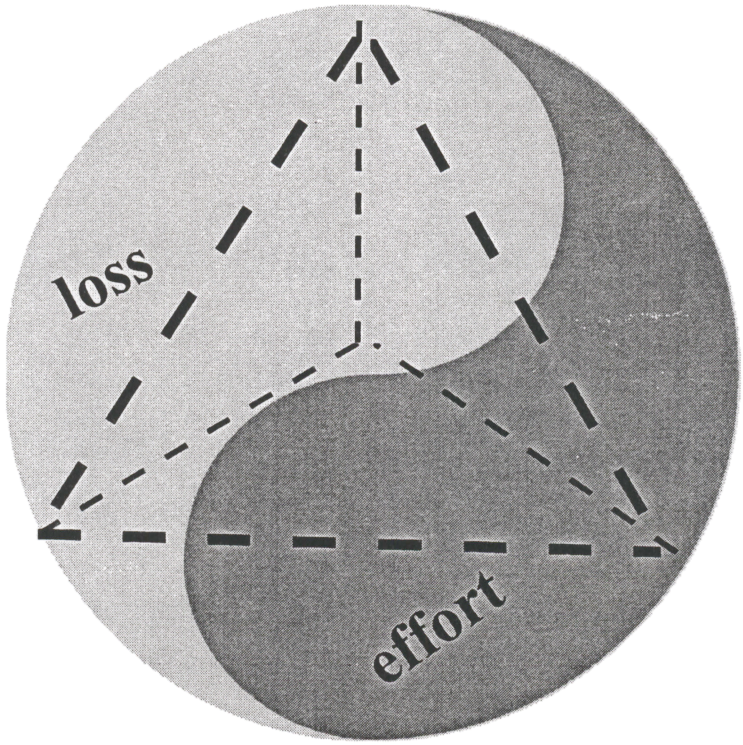

Figure 3. The ground of the thematic structure

figural, and at other times, effort is meaningful. Loss/effort relate to the existential grounds of body, time, others and world as they permeate the themes: loss/effort of control, loss/effort of independence, loss/effort of connections with others; and finally, the loss/effort in the continuity and discontinuity of self.

Loss. Loss is described through many experiences, with different meanings for the participants. Some losses are told in a matter of factly:

> there are certain things that I lost that I know now I'll never get back, but they're not things I can't live without . there are a lot of just little, little things, you know, that bug you that you don't think about. (Ida)

> had to go from contact lenses [to glasses]. I had to get rid of these because it takes two hands to put them in usually. (Rob)

Loss is conveyed in some protocols in expressions of what has been regained. Luke says of his speech, "at first, nothing," but gradually, "better, better, better." John remarks that "you just have to accommodate what you have." These were almost the same words as Harry: "so you have to learn new ways to accommodate what you have left." The accommodation of losses involves effort. Rose provides many instances of how she accommodates her losses::

> I make jello and I couldn't get it from the sink to the refrigerator without spilling it. So I'd put the dish--you know I had put it in a big dish and put the dish in the refrigerator then going to pour it in the refrigerator, you know, in the dish. So there's several ways of doing things.

Over half the participants described a loss of memory:

> the main thing is that I just, I cannot go back and remember. (Mary)

> short term memory loss is frustrating sometimes. (Rob)
>
> My memory's been like an elephant's memory. But it's, it's just the recall sometimes is a little bit harder I can't remember places and dates as quick. (Nell)
>
> but some remember and now I don't remember much. (Bob)
>
> I used to remember streets but certain streets and stuff I can't remember. (Howard)
>
> I'm just so forgetful. (Sally)

Memory loss breaks connections with others, contributes to a sense of disability and dependence on others and leaves the participants with the experience of a loss of control. Loss of memory also was experienced as a loss of an aspect of themselves.

An emotional quality to loss is woven through several of the protocols. For Mary, "it hurts to not be able to remember." Nell "feels sorry for [her]self" because she is unable to go out alone whenever she wants. Beth became teary-eyed describing her experience of intermittent loss of speech and energy as "going backwards." Rose's experience of loss began upon admission to the hospital. This left her out of control and with a profound disruption in her sense of self:

> I was just devastated that everything I had was taken away from me, you know, my jewelry, my money, and everything else you think you just never be a whole person again.

At one point, Bob says it feels as if part of his body was "cut off." He talks about a time when he was on an outing with his brother and both of their children:

> He drove the van with kids on it. He has a car, and a couple of bicycles. And they got riding and played and--I know, well, even when had both arms, that used

> to be fun and now it mad, it's still fun but it hurts a lot."

Rob gives a clear, vivid description of a time when he grieved his losses:

> "I can remember my brother when, the first time I saw him in ICU and he said, "well you're not going to run the 100 yard dash anymore." To me that really didn't hit home with me until years later when I really realized that I am not going to. It was probably a full year after my stroke that [wife] and I were riding home one day in the early fall in [mountains], that uh, I looked out of the, a really sunny day, a fall day. The colors were out and bright. I looked over at the mountains there, and I realized for the first time that I could no longer walk those mountains. And uh, that got to me and still does. And uh, I started uh, weeping that day and uh, finally, I had to pull over and let her drive and continued for about three hours crying, just grieving, and let it out and letting those emotions out. And uh, that's uh, the only time I really remember actually grieving about it.

His functional disability was experienced as a loss of the physical activity that was part of who he was.

Effort. The effort of everyday life is echoed throughout the transcripts. At times effort is a background nuisance, and other times it becomes figural and is expressed in one of the themes.

Mary had to relearn all the street names in order to resume her sales business. Julie was relieved when the speech therapist began coming to her home:

> you know the hard part was having to get ready and go, and uh, that took time of course I went in the car and [husband] took me. But I had to , say, get ready and all that. It was just really time consuming.

Rob speaks of the "frustrations" of everyday life, of:

> remembering telephone numbers, and going from one side of the room to the other you know, small events like that. .it's [frustration] always just there.

John says when he cannot recall a word fast enough, "it's like everything else, frustrating

as hell."

Effort was felt by the interviewer as participants struggled to move about, find words or recall events during the interview. For many, the unreflected, taken for granted way of being in the world now becomes a conscious effort.

> learned you just can't take something that was paralyzed for granted. (Nell)
>
> I was left-handed, and so I had to learn to use my right hand to write with. This has been frustrating and hardest task I have had to do. (Rob)
>
> the walking experience, well it was work, it was real hard work. (Nell)
>
> I have to stop and think and turn deliberately around or I will fall down. (Ida)

With regard to speech and memory, however, reflection, or thinking about what to say, was often more effortful than unreflected speech.

> you know the name of a road and can't say enough to tell somebody. (Bob)
>
> the most hard is thinking about what I'm going to say. (Howard)

Sometimes the effort is just too much. Calvin goes to bed rather than struggle trying to understand the television. Nell at times avoids fixing herself something in the kitchen because it's "such a hassle to do it." Rose emphasizes the nature of everyday work by saying,

> you have to want to do things. You have to try. .there is a way if you want to [getting better] is hard work.

John sums up the effortfulness of post stroke life: "everything I do is an experience

everything is an event you have to work at it."

Figural Themes

From the ground of loss/effort emerged the more focal themes of in control/out of control, independence-ability/dependence-disability, and connection with others/ disconnection with others. While each theme will be described separately, they are interdependent and interrelated. They are stated in polar terms, with varying experiences of tension between the poles. Time, others and importance of the situation to the person modulate the meaning of the experience.

In Control/Out of Control. The sense of being in or out of control emerged in many experiences across transcripts. The theme of being out of control often described how loss and effort were experienced. The first thing that stood out for Harry was a specific time when he was out of control. One of his early experiences with his scooter, a means of greater independence, resulted in a frightening experience when a neighborhood dog "came after me and I was trying to get away and I turned over on the scooter." A neighbor saw it happen and came to help him turn the scooter back over.

The stroke itself was seen by several as something over which they had no control. The bewildering and sudden loss of control at the time of the stroke was described by several participants:

> I said, "something's wrong," but I didn't know what . to wake up and you're paralyzed a stroke is just something that happens. it could happen to anybody. (Rose)
>
> just hit me like lightning. (Sally)
>
> I didn't really know what had happened to me. I sure didn't. (Mary)

> I lost total use of my left side, it was all gone, my arm and leg and everything. (Rob)

Julie was particularly bewildered since she took care to minimize (control) her risks:

> I didn't know what happened. But I have never had high blood pressure, I've always eaten right, kept my weight under control, so a stroke was the furthest thing from my mind but like I said, I thought people had high blood pressure and overweight and things like that if you had a stroke. It never entered my mind about that that last thing I thought of.

For many, the unpredictability of their bodies was an aspect of being out of control. Instances of unpredictability related to memory, emotions, and speech. Lack of control of speech included not only an inability to say something, but also unacceptable profanity. This unpredictability is striking in several protocols:

> I didn't have a reason to cry. I'd just, all of a sudden . (Nell)

Beth mentions an "uncontrollable temper" and says:

> I cried a lot for no reason, at least I couldn't think of a reason, I just, it was just spontaneous. I just cried a lot, it just happened spontaneously.

In another passage, she describes an instance of loss of control of her speech:

> if I got overly tired, if the situation was an exciting, happy time, a glad time, the family all together, too much excitement or too tired, I would revert back to just not being able to get anything out and I was talking like I am now and suddenly nothing would come out. I just flung myself down on the bed and said, "oh, it feels like I'm going backwards instead of forward."

Rob reports, "many times I don't have control of my emotions," and Howard says "anytime, she [wife] can just say anything to me and I could blow up." Mary's intermittent loss of memory for names leaves her out of control:

> I remembered, I remembered your name this time, but next time I won't. And it really is, it's [crying], it makes you not know what to do.

Bob's unpredictable profanity is confusing and distressing:

> I talk to him [8 y.o. son], but I use the wrong words I don't want to use them. I don't know why it does that. I know not to use it and I've even caught myself in church saying it. And I know and still can't and you try to stop it and it don't get stopped.

Calvin sounds resigned about his lack of control:

> But sometime I get mixed up I don't like it well, I don't like it. No. Nothing I can do about it.

Rob describes a time when he became "shut down when I say shut down, I mean I just can't think, I can't work, I can't function, I can't do things" He illustrates this with a story about a time his wife required medical attention and:

> my mind shut down it was kind of scary you feel helpless I was frozen, couldn't function. That makes you feel very vulnerable, especially with a man, I think.

This unpredictability reflects the person's inabilities and dependence and breaks connections with others who are experienced as discontinuous with the person's sense of self prior to the stroke.

Being out of control is experienced by some through a tempo that seems dysynchronous with those around them. Julie has to wait for her husband to do things for her: "and I want things done yesterday." While losing independence is difficult in itself, she minds not so much that he is doing for her, but that she has no control over when and how he does things. Not being able to do things for herself leaves her with:

> sort of a helpless feeling the main thing I had to learn to do, with, was I wanted things done, say, my way. Like I clean the table, I want it done this way. I had to learn that, you know, you can't do that unless you're doing it yourself like I said I have never been a really patient person, but I had to learn patience like I'm here wanting to go somewhere else. I just have to wait until he gets time to take me there.

Mary loses control of her speech when her husband does not give her enough time:

> It bothers him cause I'm not saying it right. But if he'd give me a little time, I'll correct myself, "Now F., just give me a little time and let me think about it, and then I can tell you what I'm saying."

As if to balance the loss of control, participants also spoke of experiences in which they were in control. These included mastering new skills, adapting old skills, and changing their environment. Both Rose and John saw they had control over their recovery:

> But I do think we have to have the will to live you just have to make yourself you have to take care of yourself you have to try. (Rose)

> When I was there [rehabilitation] I decided that I'm going to beat this thing-- get 95% of my facilities back you have to work at it. You can't be, you can't sit down and think it's going to come back to you. It won't. You have to have like [rehabilitation] or physical activities like you have at the Y. You have to do that. (John)

Participants use different strategies to maintain or regain control. Rob uses one strategy begrudgingly:

> Well, [wife] will compensate a lot by writing notes, do lists, things you need to remember. I resent it, but I, I need it.

Nell keeps telephones in every room in addition to a cellular phone in her wheelchair. She uses plastic dishes ("and I hate plastic") to avoid additional breakage. John "couldn't

control anything," but decided was going to beat this thing" through "hard work and perseverance." He exercises daily at the YMCA. Ida structures her days with activities. Howard, who has difficulty with numbers and money, always gives the cashier a 20 dollar bill when getting gas for the car because that way he knows he will get change back.

The strategies to maintain control serve to enhance continuity of themselves. For example, Rob's protocol frequently concerned experiences where he was organized and "in charge"; Nell was a person very involved with family and friends; her protocol was dominated by experiences with others. John was a hard working engineer who solved problems. Maintaining control was important in the sense of continuity of themselves, while being out of control was a challenge to independence-ability, relationships with others, and ultimately challenged the sense of continuity of self.

Connection with Others/Disconnection with Others. Connections with other people meant reciprocity, being with and understood by someone, and experiencing help from others. Relationships helped bridge the schism in the continuity of their lives.

John plainly says:

> the thing that kept me going was this contact with the other person . you have to have another person you have to have another person to help you get through the first year anyway.

For Nell, maintaining connections with others was paramount. The entire interview related interactions with family and friends. While keeping a telephone in most rooms and one in her wheelchair reflects a strategy for control, it also ensures she is always able to connect with others.

Rob's protocol focused on his newfound, poststroke connections with God and his second wife which he described as part of a "fulfilled life a satisfied life." These connections came at a cost, however, that of broken connections with his ex-wife, children and brother.

While most of Harry's activities are "things to do to keep occupied," his relationship with a young man in his neighborhood is one of reciprocity which gives him pleasure:

> One of my, one of my favorite things is--to do, and always has been, is I like to fish. And I have found out that I'm still able to go fishing. As a matter of fact, another fellow that lives here in the subdivision he also likes to fish. And I have a fishing boat and he doesn't have, so, so he comes down and he'll, he'll get the boat in the water for us and things like that, which I'm not able to drive a vehicle and unfortunately for him, his step-father doesn't enjoy anything like that at all. And so, I think he's trying to learn things from me, what little bit I know. And I think it's working out really well He's only an 18 year old fellow. So I'm three times his age. But the age difference doesn't seem to matter. We get along just fine But it's always an enjoyable time, just being able to get on the water. If you don't catch anything it's still a good time to me. And I think he feels the same way about it. So it's good . so I think him and I being able to get out there together and just me being able to get out there and him getting a chance to go and possibly learn some things. I think it's working out well for both of us.

This experience reflects his ability while connecting him with someone in an activity he has always enjoyed, thus contributing to his sense of continuity of himself.

Going back to work meant Ida could resume her relationships with people at work. She says that although not close friends, if you know someone "25 or 30 years even if it's just a casual friend they're part of your life." She also details experiences with her daughter and their mutual interest in crafts and sewing, again reflecting a

continuity of her prestroke self.

What stood out for Sally at the time of the stroke were the boys who came to help her: "they was the nicest things." Her relationship with her sons were described both before and after the stroke as a seamless connection. It was her sons she wanted called during the stroke, not a doctor or ambulance.

When connections are broken, the experience can be particularly painful. Bob relates a sense of disconnectedness with others when he says "I guess I want to be a part of somebody's life." His unpredictable profanity with his children and at church distances him from others: "it makes things awful." His difficulty with memory interferes with relationships as well: "I will remember I played with him [son] or maybe I won't."

For Luke, aphasia isolated him from others. He says "it a lonely house," and of the neighbors:

> And sometimes they don't understand, you know. You know uh, they don't understand stroke or don't understand aphasia or anything like that. And and so, so, and also I guess, cause I talk but I can't, so I say, you know, "forget it, I'll go sit in my room" or whatever. And it's, that is hard I think because, lonely, you know? It's, it's you know, like they try and help but they don't understand, you know?

For Luke, his computer is a "Godsend" (a phrase he mentions several times) because "just talk, me and computer and some times listen and talk and then back." With the computer, at least, he is able to achieve some symmetry in dialogue. He looks to the future for connections--a community center for people with disabilities he says is under

construction. He imagines an easy camaraderie:

> "a whole bunch, a whole bunch of, and I, and also see, also see, one dad, or uh Joe, Jim, then "let's go," this one, this one and "how you doing?" -- "oh, fine." And act instead of lonely, you know, and everything like that.

Calvin's sense of disconnection with others is profound. His relationship with his wife is altered from fatigue, aphasia, and lack of sexual intimacy. He can't even remember friends' names, and he goes to bed at 8:30 p.m. instead of his usual 10:00 p.m. because he has difficulty understanding the television.

Howard's difficulty remembering names distances him:

> Yeah, because you figure you remember your own kids names. You go to call up and talk to them every day or every Sunday. But I can't remember their name. because I get so mad, my [grand]son is only two years old, he's about two years old, I don't know exactly. But I forget his name. I can never tell him his name. I can't tell you right now. I have to get my wife and then my wife tells me. That's, you know, that's hell when you can't remember your [grand]son's name. See and that's the same thing with my boy and his girl.

Most of the participants relate times when they have received help. Connections with others are interfered with, however, when others offer help that is experienced as unhelpful. Luke talks about the frustrations when he first came home after the stroke and his parents tried to help:

> they try to help, but it's no good, cause I say look, wait, how about you say slow down, hold and time out. You try to, I can't understand. But now, frustrating because page is missing.

After five years, they have worked out how to help; they are now connected:

> But now it's OK. now it's nature, you know now it's communication.

Nell describes a time when she was crying:

> Couldn't stop it. And the kids said, "grandmother we don't want to see you cry." Or my son said, "mother, it's nothing to cry about." Well, see, that don't help at all. You don't want sympathy.

For Mary, her husband's correcting her speech interferes with her sense of connectedness with him:

> People who have never had a stroke don't understand how you feel. Hearing somebody tell you a lot of stuff. They're trying to help you sometimes I get mad at F., say "you just leave me alone, I'll think of it if you'll give me enough time." I'll be able to think of something. If I can't think of what I'm saying then I feel like if I had a little more time without somebody buttin' in telling me what to say. And maybe it's just the way he helps me or something, I don't know. .but I know he tries--I know that in his heart he tries to help. I believe, I mean he, if he just let me make my mistakes I'd be a lot better off I guess.

Several times she expresses her irritation with these corrections, but also says she depends on him. Another aspect of this theme is that his reminding her of her speech disability is a reminder of the changes in her since the stroke, of the discontinuity of herself. Though she says "I know I can never go back," his correcting her suggests he does not accept the changes.

Harry also experiences unwanted help:

> And the man, he is a good friend, and he's real conscientious guy and he doesn't, I guess he doesn't full understand how stubborn I am or whatever. But he wants to help me get up and down out of my chair. And I mean, if I, if I make a move he wants to help me do it. And I just don't like that. every time I'd try to make a move he'd think he had to help me. And I mean that's, that's nice he feels that way and wants to be helpful. But I just like to do things without help, I guess.

Julie, receiving the same kind of help offered Harry, experiences it quite

differently:

> [husband] takes really good care of me--every time I move he's there to help me. I said that's why the good Lord gave him to me. Cause he knew that I would, needed help.

Many participants mentioned other stroke survivors, with whom some felt connected.

> [a stroke survivor], I can't remember her name, I noticed the last time I went up there that she seemed, um, talk about one thing and she'd get off on something else, too, I noticed like I do kind of. (Mary)

Speaking very slowly in a quiet voice, Bob tells of his roommate in rehabilitation, an older man, whose recovery paralleled his, and who subsequently had another stroke:

> Cause he was a nice old man he was in my room and we were out [discharged] and then he back. I don't know. Cause kind of sad. Cause it could have been me. And I don't know. Here he was getting better and then he wasn't just could have been me as easy as it was him.

Sally, 93, talked of "the good time" she had at rehabilitation playing games with a ball: "and we had a lot of fun doing that. Just all of us that had strokes." Harry's comparison with the other stroke survivors, however, provided a means of minimizing his difficulties:

> I can remember when I was at a hospital here in town and I saw so many other people over there that were so much worse off than me. That it made me really consider myself very fortunate to be at least no worse than what I was.

Beth mentions several people she knew who had strokes, but did not see herself in that way:

> And one thing, please, stroke patients, if they cannot comprehend what's going on--fortunately I could, I was aware. I wasn't ever in a coma. I was aware of

> what was going on, but don't ever--tell people--not ever to let anyone talk in front of a person who's had a stroke or is in a coma. They can comprehend even though they can't communicate I could comprehend, I mean I could communicate the whole time.

Several participants mentioned encounters with the healthcare providers in the context of the stroke. Sally said of rehabilitation: "I enjoyed it. I enjoyed staying there," and the doctor was "just so good and kind." Rose, who described herself as very independent and liked to be needed, found appropriate help at the rehabilitation hospital:

> they try to make it hard. So like I said, sometimes you think they're cruel. there's a reason want to see if you can function."

When she returned for a visit, she felt connected with the physical therapist:

> he called my name. And he was so glad to see me. Of course, he embraced me. And I was glad to see him he was the one I remember most because of what he said. And he was very kind but it was true. He said I can't make you walk but I can help you walk. You have to be motivated to want to do it and that has to come from you.

Beth related a story of a physician with whom she was angry and who she felt withheld information, subsequently leaving the hospital "against medical advice." She later found another physician

> who was an excellent doctor. And he was one who would listen to me. I would go to him--from then on he was my doctor. I went to him and one day I went--and I could sit and talk to him. And he'd sit and listen.

For several participants, a lack of connection was experienced with healthcare providers. Mary's stroke followed cardiac bypass surgery. She talks of how rough the doctor was removing her sutures and:

> he didn't tell me I'd have a stroke, it gave me the stroke [crying]. They should tell people when they're going to operate on them that they may have a stroke or something he said, "well, I'm going to dismiss you," said, uh, "you won't have to come back to me anymore," so I never did go back. Some way in my heart I really resented what he, maybe I would have died, I don't know he was gone the day I was dismissed. Then I went to another heart specialist, and he dismissed me too. I guess they just getting rid of me.

Julie's experience of rehabilitation was one of not making sense:

> I had a terrible experience there I supposed to had therapy the woman was supposed to be my head therapist wasn't even there. And uh, they said I was so much percent bathtub ready. Couldn't get in and out. I didn't know they even had a bathtub. So everything they did was wrong like an invalid or somebody lesser than a whole person. .I didn't feel that way myself. They made me feel that way and uh, to me even the food they gave you, to me that wasn't things you should have. They fed you eggs and they shouldn't. To me you don't put, yellows are just pure cholesterol but, and uh, they had people over there that say, couldn't feed themselves and there to me, it should have aides or somebody right there to help them, but they didn't have.

Harry felt information was withheld from him:

> But they told me that I had reached a plateau and there really wasn't much else they could do at that time. So that's when they released me. And it was after that I found out that this is it. One thing I still don't--I really can't figure out for myself is why those people didn't tell me that I wasn't going to get any better. I mean I don't know why--I suppose I suppose the possibility that if they told people that, people might get into a depressed state over it. But on the other hand, the more I think about that, that doesn't make a heck of a lot of sense because sooner or later somebody's going to figure it out anyway--so, same boat. I just, I kind of felt like they held information from me that I had the right to know.

Howard is mistrustful:

> I mean, you can't go to, you can't go to this doctor and say geez, he's a wonderful doctor no. Cause you see them they make so many, they make so many mistakes. They put you on this or they try that. Well that don't work and they try this other and that don't work. That's, that's not knowing what's wrong, is it?

Independence-ability/Dependence-disability. Independence-ability and dependence-disability are considered here as different aspects of the same theme. In addition to using the words independent and dependent, participants spoke in terms of what they can and cannot do thereby relating to prestroke life and to the kind of person they are and were.

> I was always independent. (John)
>
> I independent. (Luke)
>
> I never ask for help if I can do it. (Rose)

For Rob, a divorce followed his stroke and he said, "I was set free," and later said God "set me free. He set me free."

Many participants spoke with pride about accomplishments, about what they are able to do:

> I felt good in all that I do in my housework. I do pretty good, and in my garden, I work in my garden. I do a lot of different things. I made a quilt." (Mary)

Rob lived alone for a period following his stroke:

> But it really got me to the point that I was really physically able to take care of myself in just about any situation.

Sally talks of her increasing abilities:

> it bothers me about walking a little bit. But I don't have to use a walking stick I can make people understand what I mean and everything--maybe I wouldn't say it in the words they would, but anyhow, I can get it over to them.

Luke has learned how to paint as a hobby after the stroke, and while his family helps

mow his lawn and do a few household chores, "that's the only thing." Bob talks about cutting the grass. There was an area he didn't do because of its difficult location. But, "finally just said I'll try it myself. And I didn't have any trouble." He also talked of a time helping his replacement at work as a mechanic. The replacement had the physical ability, but not the knowledge, and Bob had the knowledge but not the physical ability. He laughed as he said it took twice as long, but "told him what not to do, what to do. And it worked but it was good." John says "I'm getting better at everything some things I do well." Rose is willing to sacrifice time in regaining abilities and independence in activities which are important aspects of who she is:

> I was--I love to cook. And I have a son that comes by occasionally and wants--he loves fried okra, and I couldn't hold it and cut it. So I got a chopping block and just took a knife like this, you know and just slid it across it. And I could do about half of it and I'd have to go lay down and get up and start over. But I'd start about noon to have supper ready at six, but I did. And I got on the first of May--well around the first of May and his birthday is the nineteenth. And I have never failed to make him a chocolate three layer cake. And I thought, oh, how am I going to do it? But I made the cake. And I make them from scratch, not mix. So I put all the ingredients on the table and mixed it up one day and baked and then I iced it the next day.

Participants also reported struggling with the loss of independence and abilities. Rob described a time when he was not able to manage a household crises:

> You feel very helpless, uh, very inept, uh, paralyzed in thought, function, mind, body. It seems like it wouldn't do anything. I had to allow friends to take over things.

Having to depend on others is difficult:

> And uh, I guess the main thing is just him [husband] having to do everything I guess it's sort of a helpless feeling. Cause he does everything for me I

was always independent. (Julie)

I just want to be more independent I just feel like I want to do something, but I want to do it by myself I wanted to just be able to get in the car and go by myself. (Nell)

there are certain things I used to do that I can't do anymore. I hated to admit to myself that I couldn't do it anymore, but I know it's true. .but I like to try to do things for myself. As a matter of fact, I get, I get pretty upset if someone tries to help me do something, because I want to try to do it myself. (Harry)

Now I can't drive, I can't, you know, whatever, you know. I go, I go, I got to go and say, "hey, can you stop in store?" or whatever, you know. And it's hard you know, it's hard. because you know, "hey, that's OK, we'll do it." But not really, you know, not really. they're, but dependence, dependence, you know, that's a key, too. You don't want, you don't want dependence to be. I don't have independence. (Luke)

This loss of ability and independence challenges their sense of themselves and leaves less control in their lives.

For some participants, their disability becomes apparent to them through interaction with others:

I don't even know what I'm saying my wife will--would begin to point out that I do that. And she should know that I do it cause I go to and don't even realize that I've said it. (Bob)

Cause you know the name of a road and you can't say enough to tell somebody. It's, well, it's hard to tell you [interviewer] this morning. Cause I got out but I couldn't, I couldn't tell you when to turn. (Bob)

And I don't know whether that's right or not but sometimes on there, [wife], she tells me I got the wrong number. (Calvin)

Well he [husband] tells me a lot of times that what I say is not right I'm not aware of what I'm saying. I think I'm saying the right words. (Mary)

Mary is proud of her success selling home products and in this activity, does not experience a disability:

> except when I go out with [company]. I mean I sell [product] it seems like I can spill off or tell 'em about what the products are about. And uh, it doesn't seem like I make too many mistakes. I probably do, but people don't tell me. I don't know if I do or not. I mean he's listening for me to come up with something. But when I'm out with people I mean I can, I think I do all right. I don't know if I do or not. But I tell 'em if I say anything that don't sound right, tell me, you know, and they haven't told me. I don't think anybody ever told me.

However, with her husband she describes becoming aware of her disability:

> So he, he helps me a lot. He's always uh, after me if I say something wrong. He'll say, well, now what, like if I say watermelon and I'm supposed to say cantaloupe, he'll say, "now which one are you supposed to say?" Well, he tells me a lot of times that I say what's not right I'm not aware of what I'm saying. I think I'm saying the right words.

Howard, on the other hand, rejects his wife's notion of his disability with regard to his safety driving, saying, "I guess I'm a progressive driver." The connections with others serve to bridge the break in continuity resulting from the stroke; at times there is a break with others which enhances the discontinuity.

Continuity and Discontinuity in the Experience of Self. The experience of self as continuous from the time before the stroke, while at the same time discontinuous, was described by all participants. This theme arises from the sense of sameness and disruption experienced in terms of the other themes--it is a fundamental aspect of being in/out of control, independence-ability/dependence-disability, and connected/disconnected with other. While all participants reported experiencing both aspects of this theme, some

experienced more continuity than discontinuity whereas for others, the reverse was true. The degree to which other themes are figural indicates essential aspects of self for the individual. In other words, the themes serve to define self.

Mary's loss of the ability to cite the scriptures was a distressing disruption in her sense of continuity:

> I'd always went to church. I still go to church and I still read the scriptures, but I can't remember the scriptures to go back to it. Even though I read 'em. That hurts more than anything that I read, you know like if I'm reading I can go back and tell you the gist of it or what's happened. But I can't tell you the very scriptures. The scriptures that I've read. And before that I could tell you the scriptures.

Rose experienced a profound disruption in her identity around the time of the stroke, which brought tears to her eyes as she described it three years later:

> One day you're working and the next day you're an invalid. So you know, you think you're through you think you just never be a whole person again when you realize you're paralyzed just like I said, it was devastating. One day you're who I was, you know. You're in business and you're running a business and you're a grandmother and a wife and you drive, you go anywhere you want to, write a check, buy groceries or whatever. And the next day you're flat in bed, helpless . you were in jogging clothes and no make-up and I couldn't do my hair properly, and being a beautician, that was degrading . and you're stuck in the hospital with a lot of depressed looking people. And you go to breakfast and they're sitting around, you know, depressing. And some of them have been in wrecks, with tubes in their nose and all this. It's not the atmosphere that you're used to. And you're one of them. That's the bad part

Doing for and being needed by others was an important dimension of who she was, and the stroke threatened that: "It would be awful to be in bed all day and not be missed, if

you're not needed." Her struggles after the stroke were in trying to regain this sense of herself.

Harry's identity was integrally tied to his ability to work. For him, recovery meant returning to work. A few years previous to his stroke he had an accident which left him with a severe hearing loss, but he viewed his recovery as full recovery because he was able to go on with his work. The longest passage in his interview was when he was discussing the different kinds of jobs he had and his increasing responsibilities. The inability to work following the stroke left him feeling diminished:

> I was just, I guess really, I was kind of feeling a little sorry for myself. Why me? You know, that kind of thing. And just because I wasn't, I wasn't able to work and I wasn't able to do things like that. I just, sometimes you thought, well, you're useless just due to the fact I suppose, you know, like I said, my work has always been real important to me."

He was a person who had always been busy, and now, "I'm not as busy as I'd like to be."

Not remembering leaves Howard feeling "lost" at times. The stroke has changed how he is in his world:

> I don't feel tired and lazy. I just don't want to do it, period I did it all. I cut the grass and everything around here. I don't do that no more--trim our bushes and things and the wife and I did a lot of those things and I'll sit and watch her now and let her do it. I mean, I don't care. I think that's part of it, I mean, stroke.

Participants frequently described their bodies differently often referring to their body in the third person. For example, Calvin doesn't sweat, food tastes "all the same," and he has no sensation in his arm. Ida's discontinuity in the experience of her body is described in over five pages of transcript:

> one of the things that I think I had talked to you about besides the little knots under the skin on my right side, was that my entire left side--you could've sliced me right down the middle and that's where it came to. Was a feeling of uh, that you'd been scalded I have had a lot of problems with coughing I think the throat tended to relax or something. And then eating was such a really awful experience. it's like trying to swallow a bowling ball. It just doesn't want to go down and it's just the little epiglottis just doesn't close up and you swallow down the wrong way.

Other examples of third person reference to body include;

> You don't turn that hand loose if you've got it up over your head that's no problem now cause I can hold the hand I don't trust this hand. (Nell)
>
> The brain just no work. (Luke)
>
> It was already numb, you know, clear down the whole side .I turned over on the left side I can't do with that leg and the hand's the same way. (Sally)
>
> I don't know why it does that. (Bob)

Even the least articulate participants were able succinctly to note the disruptions in themselves:

> I changed, it seemed then just turn around and you've lost part of what you are. (Bob)
>
> I haven't got all my brains . there's one missing up there. (Howard)
>
> It's all different. did something to my mind I don't know, I just, uh, well, it's not always like I used to. (Calvin)
>
> It had changed things. (Julie)

The stroke brought about changes in participants; some of the changes were experienced as beneficial. For example, Mary says that her prestroke life was a cycle of ups and downs in energy and emotion, but after the stroke, her life was on a more even

keel. Another participant (Harry) noted that he lost 60 pounds which he kept off, and became more extroverted:

> it seems that they were more or less, I don't want to use the word happy that I'm that way, but they didn't seem put off by the fact that I talked more and was a little more open. So everything, all the side effects from this are not bad, I guess.

Rob fit the stroke into the flow of his life: "it was oh, kind of a culmination of a lot of things. I guess the stroke was the final straw." But this final straw was a powerful catalyst for profound changes in his life. Prior to the stroke he was "mentally trapped" in his marriage and paradoxically, becoming "physically trapped" after the stroke was what "set me free":

> [I had] a Damascus Road experience, like Paul did, going to Damascus, it was really, just when he sings I was radically saved, radically changed for the first time, I think, uh, really had hope in my life. And I guess the whole of my soul was filled up I don't have to be the macho man I used to be. Uh, I don't have to prove myself and here I am today, 14 years later, living a life that is very satisfying. Frustrating occasionally.

Not all participants spoke of the events surrounding the stroke event, but those who did expressed a sense of retaining the essence of who they were.

> I was aware. I wasn't ever in a coma. I was aware of what was going on I could communicate the whole time. (Beth)

> I never lost consciousness. (Ron)

> I guess they think because you can't do things your mind is affected. But mine never was I never had any problems with my mind so there wasn't anything wrong with my mind. (Julie)

> and I could talk. I could tell them whatever they wanted to know. I still had my mind. I just couldn't think lots of times. (Sally)

> I was aware of what was going on. I asked her later if I was ever totally out of it. And she said, " I don't think so." Said, "I don't think there was a time you didn't know who you were." (Nell)

Participants noted changes in themselves, some of which they tried to locate in the natural flow, or continuity, of their lives:

> Short term memory loss is frustrating sometimes. I think all stroke patients suffer from that to different degrees. And uh, I don't know whether that is just a natural part of my age or it is, you know, part of the stroke, uh, I know lots of people that say, well, I had the same problem, and I think it is just my age. But, I don't know. (Rob)

> I've had this [forgetfulness], course everybody has things. (Calvin).

> I'm 72 years old you don't expect that your golfing, you're golfer that you were before. Or dancer that you were before. (John)

> But I am awful forgetful. But most people are to some extent I've been awfully hard of hearing since then [the stroke]. But I think I was beginning to have it anyway, hard of hearing, you know. (Sally)

> And I don't know whether it's [dry eye] just because of my age or it's because of the stroke. (Ida)

While disruption in the continuity of their experience of self was seen in all the protocols, so was a sense of continuity. This was expressed in a variety of ways:

> I can't turn around and tell somebody else what I've read. I mean I've always been that way. I was that way before. (Beth)

> I'm a chemical engineer. (John)

> Cause I'm the sort of person if you tell me not to do, I go do it, just as a challenge. (Rose)

> I have always enjoyed cooking, so I fix dinner for all of us every night and it's ready when they get home. (Harry)

> Cause I'm computer expertise. but this is, I can type and stuff like that. (Luke)

> I've always been kind of a knot head pretty stubborn she [wife] knows I'm a knothead so she kind of figures I'm going to want to do things for myself she knows how I am about certain things. (Howard)

Often, continuity was experienced in terms of relationships with others. This was exemplified by Nell. She was a person whose sense of self was experienced dialogically through interactions with others. Her lengthy interview was brimming with quotes of conversations with others. Though confined to a wheelchair following the stroke, her ability to interact with others was experienced as unchanged.

Mary's sense of continuity is bridged to her poststroke life through her relationship with her husband. Though his correcting her speech breaks the connection between them, paradoxically, it maintains the continuity: "oh honey, he's always told me what to do." Their way of handling discord has not changed:

> That's what me and F have always done. If he gets excited with me, he goes, and if I get excited with him, I get out and go someplace.

Julie maintained a sense of continuity in the presence of marked change. She noted that her "mind was never affected." Although she required the assistance of her husband in all activities of daily living, she said, "after the stroke I still could do things like I always did." Her husband attended to all of the details, including putting on her make-up every day, and taking her to the hairdressers' every week, thus maintaining her continuity: "he knows the way I am." While she said those at rehabilitation "treated me as lesser than a whole person," she "never felt that way myself."

Work was the expression of identity for several of the participants. Although Harry was unable to return to work he experienced some continuity through his work:

> it makes me feel good that I still have people that I met while in that position, a lot of them still call me at home here when they have a question or whatever. So that makes me feel pretty good.

For Ida, the return to work was experienced as affirmation of herself and the sequelae of the stroke were experienced as minimized, because "getting back to the same old, same old [work]" was what was important:

> I am one of those people that my self image really has to do with my work, so that's one reason that it was go great for me to go back.

Her job responsibilities changed because of the stroke, but she still felt

> they basically treated you as though you were a competent person and allow you to do your work so apparently they don't feel sorry for me, and I enjoy that.

While she described many changes in her body and how they affected eating, sleeping and moving, the return to work provided continuity:

> I don't think there's anything really spectacular about, you know, the differences after the stroke or before the stroke. The thing is to pretty much live your life almost as you did beforehand.

The experience of continuity and discontinuity is seen throughout. Calvin's difficulties with remembering names and his lack of sexual intimacy with his wife, which are distressing to him, had their origins in his prestroke life. However, the stroke magnified these problems so he experienced himself as both the same and different. The tension between experiencing a sense of continuity while at the same time a discontinuity

of self was most poignantly expressed by Bob:

> I just now noticed it. I don't know. You, you, look around see all you are to different people. And that's good. Then just turn around and you've lost part of what you are. and really you haven't lost it. We're the same people .yeah, you're not missing but you are. And I don't know how it is. Cause you--I just now notice but you, I don't know, it's hard, especially now. Cause I'm feel like I'm missing a bunch, but I'm not I just hadn't really set down and thought out how that was different but it is all same. It's, it kind of, it kind of different but all the same.

CHAPTER FIVE

DISCUSSION

The purpose of this study was to investigate the experienced quality of life following stroke as described by the survivor. While most previous studies have studied quality of life from the standpoint of a grade of excellence, this study focused instead on the nature of life following stroke. An existential-phenomenological methodology was used involving an in-depth interview, which began with the question: Please describe specific experiences since your stroke which stand out for you. A thematic analysis of these interviews revealed that the world of the stroke survivor is grounded in experiences of loss and effort, which are inextricably connected. From this ground emerged these interrelated themes: in control/out of control, independence-ability/dependence-disability, and connection/disconnection with others. Taken together these themes combine to form the essence of the experience, which involves an experience of continuity and discontinuity of self. The purpose of this chapter is to discuss the results of the study and their implications for nursing.

Stroke is one of the leading causes of disability, and stroke survivors are often the most frequently encountered patients in rehabilitation. Improving the quality of life is the overarching goal of rehabilitation and an important concept in the ARN Standards (1995). Despite this focus, quality of life in stroke survivors has been studied from a mechanistic,

normative, functional perspective which seems antithetical to nursing's more holistic perspective. Functional abilities and disabilities, while important in establishing rehabilitation goals, have meaning only in the context of an individual life. Taken out of this context, it is not surprising, therefore, that DeHaan, et al. (1993), found no correlation between QOL and stroke severity, disability and handicap, although the latter three were highly correlated. Similarly, it is not surprising that Ahlsio, et al. (1982) found no improvement in QOL in stroke survivors whose functional abilities improved. The rating of quality of life in those studies were based upon decontextualized categories and therefore give no understanding of the nature of the stroke survivors's existence. Results of the present study indicate that the quality (nature) of one's life following stroke is based on the continuity in the sense of one's self.

Thematic Structure

Loss/effort

The concept of loss has been described with regard to coping (Adams & Lindemann, 1974) and to grief with respect to loss of functional abilities (Benoliel, 1971; Werner-Beland, 1980). It is not difficult to count the losses of stroke survivors' functional abilities. How these losses present to the individual, however, is unique and can only be understood from the survivor's perspective. If a stroke survivor is grieving or trying to cope with the functional loss, it would be important to understand what the loss

means for that person.

Mumma (1986) categorized perceived losses following stroke according to hemisphere of injury. She noted that those with right brain injury listed "independence" as the first of 5 rank ordered losses and wondered why this was not mentioned by those with left brain injury. The losses listed by the left brain group were: mobility, driving, fishing, hunting, communication and physical abilities, most of which could indeed be experienced as loss of independence. Having the individual talk about what stands out for him/her helps providers understand what is important. Fishing and hunting could mean welcome solitude, challenge, or a time to be with friends; thus, the loss of these abilities have many potential meanings and this was certainly true for participants in the present study who had similar functional losses.

For three of the participants, the inability to remember street names and/or directions was an important loss and interfered with their sense of independence and control. Tuan (1977) differentiates space from place in that the former is open and free, and the latter is defined and secure. Loss of street names and directions would thus transform the once familiar, secure places into unfamiliar open spaces--a formidable prospect for one trying to reintegrate and renegotiate the world. Renegotiating one's place is effortful.

Effort was figural in Doolittle's (1990) ethnography of stroke survivors, not surprising in that her participants were just beginning the arduous task of relearning how to maneuver in a world now filled with obstacles. Even after rehabilitation, as this study

indicates, effort remains the ground of the stroke survivors' world. While rehabilitation may mitigate some of the functional losses, it is still with effort that the stroke survivor negotiates with these losses.

Independence-ability/dependence-disability

Independence-ability is highly valued in American society so it was not surprising that this theme emerged. What independence-ability meant to the participants, however, was individual. For example, what was figural to Nell, who is wheelchair bound, was not an inability to walk or garden, but her ability (not disability) to manage her, albeit different, household. She had adapted her routines to her abilities. Receiving help for shopping, cleaning and other chores was not bothersome; not being able to go off by herself when she "felt like it," however, left her feeling dependent-disabled. Harry, on the other hand, found his inability to do meaningful work figural in feeling disabled. He was able to participate in many activities independently, but they were merely "things to keep occupied"--a lesser substitute for what was really important to him. Although Nell and Harry had similar physical limitations, the meanings for them were vastly different.

An important finding was that much of the disability experienced was unseen. Several participants had marked hemiparesis with physical limitations, yet this visible reminder of the stroke was often just mentioned in passing as the context of a meaningful situation. Conversely, while several participants were referred for the study by people who commented that the stroke survivor had fully recovered, the participants so described continued to experience the consequences of the stroke. Several had recovered

most or all motor function but continued to suffer from speech and/or memory disabilities (e.g., Mary, Calvin, John, Walter) which enhanced their sense of discontinuity.

In control/out of control

Doolittle (1991) found loss of control thematic in her ethnography of stroke survivors. Experiences which led to that loss of control centered on the uncertainty with respect to hospital routines and the evolution of the stroke. In this study, participants continued to feel out of control in some aspects of life long after hospitalization. Even though the out of control situations changed, the experience did not. Unexpected profanity was described by several. For Bob, these outbursts deeply affected his interactions with his son, wife and church members. Both he and Beth were surprised to learn after the interview that this was directly related to the stroke. All participants, however, also experienced some control in their lives and many had developed strategies for their unique situations, e.g., Howard using only twenty dollar bills to ensure that he gave enough money to fill his gas tank. Whether these were learned in rehabilitation or on their own was not disclosed.

An assumption of the researcher was that participants would be living under a cloud of the possibility of recurrence of stroke, and in fact, Doolittle (1991) noted this concern in stroke survivors in the six months following the stroke. This seemed not to be the case, or at least it did not surface in the interviews; however all participants were well past Doolittle's time frame. Only Sally, age 93, said her doctor warned her of recurrence, but she did not seem to take the warning seriously: "everybody makes mistakes." She

hoped to live to 100.

Connection/disconnection with others

In Phenomenology of Perception, Merleau-Ponty (1962) concludes with the quote: "Man is but a network of relationships, and these alone matter to him" (p. 456). The primacy of this network of relationships was certainly woven throughout the transcripts in this study. The connection or disconnection often brought to focus the sense of continuity or discontinuity of self. Julie maintained a strong connection with her husband who maintained her continuity. Broken connections also broke the continuity of self. It was often through others that a disability manifested. For example, Mary was only aware of using "wrong" words when her husband told her; Bob's profanity was a problem only when he was with others; Rose's struggles were when she was trying to do for others.

The rhythm of participants' lives changed following the stroke. While this altered their control, it was often experienced through interactions with others. Rob, who once was responsible for a large dental practice, couldn't make decisions fast enough when his wife needed medical attention. Julie had to wait for her husband to "learn to be patient." Rose made allowances for the greater time it took to do things for others that she once took for granted. For those with aphasia, the tempo of their speech was drastically altered. Rather than take the effortful time to communicate with his neighbors, a difficult task, Luke often stayed by himself. Interestingly, he several times mentioned what a "Godsend" the computer was. The computer, then, became the other for whom

tempo was of no consequence.

All participants had been hospitalized at some time during their stroke experience. Considering that a primary reason for hospitalization is to provide 24 hour nursing care, it was striking that nurses were barely mentioned. Participants who did mention nurses were describing situations in which they felt estranged from the caregiver. Mary said it was a nurse who told her husband to correct her speech and this advice was apparently taken to heart by him and served to break Mary's sense of connectedness with him. She also briefly mentions a nurse trying to remove sutures, and the doctor taking over in a rough manner. The nurse apparently made no effort to intervene. Beth recalled a time prior to the stroke when she was trying to leave the hospital after two weeks of studies about which the doctor was not informing her. She remembers the nurse with a clipboard demanding she sign "against medical advice." In none of these instances did the participant feel supported by the nurse.

Encounters in rehabilitation were figural for only three participants. Sally thought everything was "wonderful," but it was the other patients to whom she referred; Rose said "you think they're cruel. There's a reason"; and Julie thought going to rehabilitation was the worst mistake she ever made. Ironically, she said it "cost her an arm and a leg." Many mentioned physicians with several describing experiences in which they felt a sense of betrayal or mistrust. What seemed to be missing was participants' overall lack of connectedness with health care providers. Considering the amount of contact with providers whose intention is to support, this finding was surprising and disturbing.

Continuity and Discontinuity of Self

Erikson (1980) views identity as a reassuring continuity in the face of change. For stroke survivors, unexpected, unplanned change occurs; the changes that occur disrupt continuity by changing how the person is in the world. The propensity of the consequences of a stroke to disrupt the person's experience of connections with others, independence-abilities, and control affects the person's sense of continuity of self. The degree to which these themes are figural to the person will influence the sense of continuity and discontinuity. Several participants located changes in the natural flow of their lives rather than to the stroke itself thereby providing some reassuring continuity to their lives. For example, memory loss was often attributed to stroke and to age.

The experience of both continuity and discontinuity was bewildering for some participants. While Bob was most articulate in this experience, he was not alone. The person who experienced the greatest discontinuity was Calvin, whose stroke was most recent. He was fully functional in activities of daily living, but his speech and short term memory were impaired and he had altered body sensations. This so affected his sense of himself that he had considered suicide.

Merleau-Ponty (1962) points to the difference between the lived body, or the first-person experience of the body, and the third person view of the body as object. The person both has a body and is a body. The experience of one's body as lived is not separate from one's experience of self, and as stroke survivors experience their bodies differently it changes them. Several participants spoke of their bodies in disembodied

terms as though not their own.

The rehabilitation view is from the third person perspective, in which the body (object) of the stroke survivor is either functional or nonfunctional. The emphasis is on "fixing" or adapting to the nonfunctional. While these adaptations improve the individual's abilities, the person's sense of discontinuity may not be lessened without attention to the meaning these changes have for the person.

Implications for Nursing

Nursing Practice

Nursing's Role in Rehabilitation. The results of this study have implications for the role of nurses in rehabilitation. The current focus in rehabilitation often decontextualizes or disembodies the impairment from the person thus neglecting the fundamental interrelatedness of human experience. While other disciplines in rehabilitation, such as physical therapy and occupational therapy, have clearly defined boundaries the role for nurses has been less clear: human experience, in all its complexity is not well bounded. The virtual absence of nurses in the protocols suggests, at best, a peripheral, if not invisible, role. Yet nursing, as the one discipline having prolonged interaction with patients, has much to offer.

All nursing theorists, from Nightingale forward, have emphasized holistic care of the person. An holistic approach seems particularly important in rehabilitation where

patients are learning how to reintegrate their lives after an often catastrophic, life changing event. Lydia Hall, a visionary nursing theorist and pioneer in rehabilitation, clearly saw what nursing could bring to a person's rehabilitation experience. She brought her ideas of patient-centered care to life in the Loeb Center, a nurse-run rehabilitation unit in which nurses facilitated patient decisions and goals (Loose, 1994). Unfortunately, she has not received much attention in the last few decades, and was not even mentioned in a recent review of nursing's role in rehabilitation (Kirkevold, 1997). Her ideas are especially relevant today in a health care system in which an individual's care is divided among multiple specialties.

One of the existential grounds of human experience is "others." Considering the time rehabilitation patients spend with nurses, it was unsettling that nurses did not emerge as figural from this ground, that nurses were not experienced as positive forces in rehabilitation. Indeed, it was as though nurses did not exist. They did not meaningfully connect with these participants, and could possibly have contributed to their sense of discontinuity by not understanding the individual meanings of the changes heralded by the stroke.

The thematic structure described by participants in this study provides a perspective from which patients' experiences can be better understood. This understanding, in conjunction with nursing theory-based practice will move rehabilitation nursing toward fulfilling its holistic mandate.

King's (1981) theory of goal attainment provides guidance for nursing's role. The cornerstone of this theory is mutuality, with an underlying assumption that perceptual congruence is necessary for transactions and goal attainment. King (1981) states: "if nurses with special knowledge and skills communicate appropriate information to clients, mutual goal setting and goal attainment will occur" (p. 149). Goal setting in rehabilitation, however, is based on functional abilities and disabilities of the individual, often out of context with the person's life. The patient is often a peripheral participant in the goal setting process. The "special knowledge" gained from this study is a perspective through which a different understanding of stroke survivors and their experiences is possible. Rather than focusing on functional disabilities, the thematic structure provides an holistic view of the experience; nurses could explore realistic ways for the individual to recapture the continuity of self, thus offering a greater possibility of mutual goal attainment.

As recovery from stroke evolves, so too do figural events and their meanings; goal setting cannot be a one time, fixed event, but rather ongoing as the meaning of life experiences following stroke unfolds. These characteristics of human experience also have implications for a broader role for nurses. While continuity of care is a much touted phrase, care is, in fact, compartmentalized by current health care settings. Advanced practice nurses are in a position to cross health care boundaries, following patients throughout the illness experience. In a study of individuals with chronic illness, being "known" by the caregiver, in this case nurses, fostered self confidence (McWilliam,

Stewart, Brown, Desai, & Coderre, 1996). Coming to know the person over time would provide consistency in helping the person regain continuity of self in the experience of surviving a stroke.

The role of nursing in rehabilitation has been viewed by many as supportive of the other disciplines, but with no clear therapeutic role of its own (Kirkevold, 1997). Nursing theories and models, however, provide much guidance. If nursing is to move beyond this merely supportive role for others, nursing administrators must embrace theory-based practice with its holistic base. The thematic structure of life following stroke complements nursing theory by providing a foundation for understanding the world of the stroke survivor.

Practice Strategies. The results of this study offer several strategies for nursing practice. The literature is replete with ways to categorize or stereotype stroke survivors, which lead to standardized interventions. An example would be the categorization of the behaviors those with right and left hemisphere brain injuries. While these categorizations may be useful, they are limiting in that they neglect the meaning for the patient.

With the essence of the stroke experience as a sense of both continuity and discontinuity of self, it would be important to assess what is meaningful to the individual, so that goals could be mutually developed which enhance the person's sense of continuity. Dialogue must be ongoing as meanings evolve and change. As stroke survivors struggle with change, nurses can contribute to continuity at the very least by maintaining some consistency in who provides care.

Nurses are socialized into "doing for" others, and in rehabilitation this role is shifted to teaching and facilitating the patient to "do for" himself. What is often required of the patient is what caregivers deem as important, overshadowing what may be important to the patient. An empathic presence to the stroke survivor's experience may be as important as doing, and could facilitate a connection and meaningful goal setting.

Therapeutic effects of the phenomenologic interview in research have been reported in the literature (Hutchinson, et al., 1994 and this was evident in this study as well. Bob, in particular found new insights into his experiences as he repeated: "I just now thought of this [that he was the same person]." All of the participants thanked the researcher for her time, emphasizing the need in this population to be heard.

This interview technique is well suited to nursing situations. Nursing seeks to understand an individual's experience. Nursing encounters with patients are often reduced, however, to specific information seeking and giving; much of the information sought is in regard to neurological impairments. We tend to monitor deficits rather than personal strengths and/or things that matter to the individual. The phenomenological interview shifts the focus to what the patient wants to convey. This can then be useful in designing rehabilitation strategies which are meaningful.

The power and elegance of the phenomenological interview was demonstrated in this study. An unusual aspect was the inclusion of individuals with aphasia and memory deficits. Many studies of stroke survivors have excluded such individuals because of difficulties with interviewing, recall, and ability to accurately complete instruments. In

seeking to understand the perspective of the stroke survivor, however, these difficulties become irrelevant. While their sense of disconnection was perhaps more figural than for the other participants, the thematic structure was consistent for both those with and without aphasia and memory loss.

People with aphasia lack conversational power to shift or adapt their patterns of speech to "normal" conversation, and may thus limit their interactions. The tempo of the other creates an imbalance in the interaction so the experience of the disability is enhanced, thus breaking connections. Certainly participants with aphasia in this study had a tempo different from everyday conversation, yet, this interview form was conducive to meaningful dialogue. The interviews with Luke and Bob, both with nonfluent aphasia, lasted 1 1/2 hours and both were fully engaged throughout. Luke used his left hand and fingers on the coffee table to indicate relationships, place and movement as he told his experiences--it became a sort of short hand or sign language which the interviewer was able to understand. Rather than use the person's limited speech resources in answering questions which mainly serve the provider, nurses could use phenomenologically based interview techniques in communicating.

Nurses can play a substantial role in reconnecting stroke survivors with others. The disconnection from others experienced by these participants was not because of lack of contact. Rather, it was a lack of understanding. Unhelpful "help" by others was described by several participants. Such help was based upon misunderstanding of what the stroke survivor needed and/or wanted. Helping patients and families understand

aspects of the stroke, such as profane outbursts and heightened emotionality, may mitigate the shame and confusion expressed by some participants. Corrective help, e.g., with speech, was particularly unhelpful. While it is likely that the participants and significant others had been told about these effects, they obviously needed continued reassurance.

Another reconnecting strategy was suggested in Luke's protocol. He several times mentioned how the computer was a "Godsend." What often seems to disconnect those with aphasia from others is a difference in conversational tempo. The computer makes no demands on time. For those who are able, computer discussion groups could provide a means to connect with others without time constraints or correction.

The thematic structure provides a way of understanding the survivor's perspective to promote the person's sense of continuity and wholeness. Specific strategies for nursing practice can focus on what is important to the person, not on a predetermined schedule based on generalizations about type and location of stroke. As the other rehabilitation disciplines teach specific motor and linguistic skills, nursing can help patients integrate these skills into meaningful experiences.

Nursing Education. Nursing has made great strides in using nursing models and theories although nursing education continues to be based on the medical model. While nursing models are usually taught somewhere in undergraduate curricula, they are often apart from practice, so that their use remains academic. Such a lack of emphasis may contribute to nurses focusing on tasks rather than on people. In the last few years, this

focus has contributed to the replacement of nurses by unlicensed personnel who are easily trained to complete discrete functions. If nursing is to fulfill its professional mandate to provide holistic care, the focus must shift. Curricula based on a nursing model will greatly facilitate a holistic focus in which meaning for individuals becomes paramount.

Education for advanced practice nurses could include creative ways to structure roles in order to transcend health care system boundaries. Unfortunately, the current impetus toward nurse practitioners facilitates the medical model for a nursing practice which is confined to specific settings. Rather than the health care system driving nursing education, advanced practice programs could take the lead in developing roles which enhance vulnerable individuals' sense of wholeness.

For nurses currently in practice, inservice education can assist in helping focus on individual meanings, and less on classifying according to disease or deficit. The thematic structure provides an alternative way of teaching about caring for stroke survivors. Additionally, teaching nurses techniques of phenomenological interviewing will greatly facilitate an empathic presence with patients. Results of this study support what nursing has always espoused, namely, an holistic view of the person. It is incumbent on nursing educators to help nurses live this philosophy.

Nursing Research. Future nursing research with stroke survivors focusing on meanings and things that matter to the person should serve to guide nurses in improving quality of life. Several studies are suggested by this research. For one, it was surprising

that healthcare providers were infrequently mentioned, particularly nurses. Our current way of inbteracting and gathering information may be frustrating to stroke survivors, particularly those with aphasia. How do stroke survivors feel after encounters with nurses? Do they have enough time to say what they wanted? Do nurses and others contribute to their sense of discontinuity through a focus on disabilities and impairments? A study looking at experiences with nurses in rehabilitation that stand out for stroke survivors might provide useful information.

A study comparing different approaches to goal setting with stroke survivors could provide guidance in finding ways to enhance the sense of continuity of self. One approach to goal setting could be through the use of a phenomenologic type interview. This type of interview requires the nurse to be present to the stroke survivor's experience. It may be that empathic presence, a connection, is what will make a difference in their lives.

Nurse facilitated support groups could be helpful, particularly for those patients whose disconnection from others is a figural aspect in their sense of discontinuity of themselves. A future study could assess the impact of such a group on the stroke survivors' connectedness with others and sense of continuity.

Because connection with others is so integral to the experience of stroke survivors, it is important to understand the experience of significant others since their lives also change. A future study using this methodology with significant others would offer insights for nurses in helping families develop strategies to meet goals that are truly

important to them, and facilitate the reintegration of the stroke survivor and significant others.

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APPENDICES

APPENDIX A: IRB Approval

THE UNIVERSITY OF TENNESSEE
KNOXVILLE

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05/07/96

IRB # 5059 B

Title The Quality of Life Following a Stroke: The Stroke Survivor's Perspective

Secrest, Janet A.
Nursing
1711 Mountain Bay Dr.
Hixson, TN 37343

Thomas, Dr. Sandra
Nursing
1200 Volunteer Blvd.
Campus

Your project listed above was reviewed. It qualified for expedited review and has been approved.

This approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The Committee wishes you every success in your research endeavor. This office will send you a renewal notice on the anniversary of your approval date.

Sincerely,

Steven B. Pulik
Coordinator of Compliances

cc: Joan Creasia

APPENDIX B: Informed Consent

INFORMED CONSENT FOR A RESEARCH STUDY ENTITLED

"THE QUALITY OF LIFE FOLLOWING A STROKE: THE STROKE SURVIVORS' PERSPECTIVE"

You are invited to participate in a research project. The purpose of this study is to explore the experiences following recovery from stroke. The results of this study will help nurses better understand stroke survivors. The interview will be conducted by a nurse who is also a doctoral student at the College of Nursing at the University of Tennessee, Knoxville, TN. This study is being conducted as partial fulfillment for a doctoral degree.

You are asked to participate in an audiotaped interview that will last approximately one hour, in a place of your choice. You will be asked to share your experiences following your stroke. Subsequent questions will be based on your comments and responses. This interview will be audiotaped so that the investigator can use your exact words to compare with words of other spouses/significant others. Your name will not appear on the tape or the transcript, and will be known only to the investigator. You may be contacted by the investigator following the interview during the analysis to clarify the interpretation of your experience, however the analysis of the spouse/significant other interviews will not begin until after the stroke survivors' are completed. The tapes and transcripts will be kept in a locked file at the University of Tennessee, Chattanooga in the School of Nursing. The signed consent form will be kept in a separate locked file for three years after the study. Upon completion of the study, the tapes will be destroyed. The transcripts may be used at a later date for further analysis, but at no time will they be traceable to you. No incentives are offered to you for you time and effort in participating, however, you may personally benefit by talking about your experiences. You may contact the investigator following the interview at the number listed below if you wish to discuss the interview or clarify the interpretation of your experience.

The nature and direction of the interview will be determined by you and the investigator, and will unfold as the interview progresses. You may have concerns related to the potential sensitivity of disclosure of your personal experiences and feelings. You are free to not answer any questions regarding these feelings. You are free to choose not to participate in this study or you can withdraw without penalty from this study at any time either during the interview or following the interview by notifying Ms. Secrest. Your audiotape and/or transcript will be destroyed upon your request.

Any and all information you provide will be kept in confidence. Neither your name nor any identifying information will be used in any reports although your words may be used to support the interpretation and analysis. At no time will your words be linked or traceable to your name.

Project Director: Janet Secrest, RN, MSN
School of Nursing
University of TN, Chattanooga
615 McCallie Avenue
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(423) 785-2131

CoDirector: Sandra P. Thomas, RN, Ph.D.
College of Nursing
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(423) 974-7581

This study has been explained to me and I voluntarily consent to participate. I have had an opportunity to ask questions and understand that I may ask further questions at any time in the future by contacting the investigator named above.

_____ _____

(SIGNATURE) (DATE)

APPENDIX C: Confidentiality Statement

AGREEMENT TO MAINTAIN CONFIDENTIALITY

I, _____ agree not to discuss or disclose any of the content of the transcripts analyzed by this qualitative research group for the study entitled: "The Quality of Life Following a Stroke: The Stroke Survivors' Perspective."

Name: _____

Date: _____

APPENDIX D: Demographic Data Form

DEMOGRAPHIC DATA: STROKE SURVIVOR

ID# _____

1. Age: _____
2. Sex: _____
3. Marital Status: _____
4. Work/retirement status: _____
5. Family income: _____ < $10,000/year
   _____ $10,000-24,999/year
   _____ $25,000-49,999/year
   _____ $50,000-100,000/year
   _____ >$100,000/year
6. Number of people living in household _____
7. Months since stroke _____
8. Date of discharge from rehabilitation hospital _____
9. Hemisphere of stroke _____
10. Activities of daily living which require partial (P) or total (T) assistance:

_____ Eating _____Dressing upper body _____Dressing lower body
_____Grooming _____Bathing _____Bladder management
_____Bowel management _____Transfer to chair _____Transfer to toilet
_____Transfer to tub or shower _____ Walking, level ground _____Stairs
_____Wheelchair

APPENDIX E: Sample Transcript: ROSE

I ....well that's what I'm interested in. If you could please describe for me specific experiences you've had since your stroke that stand out for you.

S Well, they say--is this going now?

I Yes, it's going.

S They say--what day of the week is this? They're testing your mentality, you know, to see if you can remember. And who's the president and what month is it and all this they ask you.

I And how was that for you?
S Beg pardon?

I How was that for you to be asked?

S Well, first of all I was just devastated that everything I had was taken away from me, you know, my jewelry, my money, and everything else.

I Your personal belongings.

S But it got better.
I That was really difficult for you.

S Yeah, one day you're working and the next day you're an invalid. So you know, you think you're through.

I You think you're through?

S You think you just never be a whole person again, when you realize you're paralyzed. When you can't move a finger or anything, you know? But you just have to, just pray about it and you'll get better. So...

I You didn't feel like a whole person?

S Well, ?????? you know.

I Why you...

S I'm a person that tries to do the right thing for everyone, you know, take care of everybody. And I just couldn't understand it. I'm sorry I get emotional. But they tell me that goes with it. But uhh, I just made up my mind and I prayed to die. But I said if I can't get better I want to die. And if I can get better I will. And just immediately, I started getting better. And like I said before, you have to want to do things. If you want to sit in a wheelchair okay. So my husband pushed me down to therapy the first day. And this big--this large black man approached me and he told me his name, and said "I'm here to help you. I'll teach you to walk." He said "you'll stand up and I will hold you and we'll go around with the walker." And I said I can't do that. He said "well, you, you have the right to choice. If you don't want to that's your right. But I've never let a person fall. And I wanted to help you. But you have to be willing to do it or you can sit in that wheelchair the rest of your life. It's your choice." Then so immediately, I said well look, you know, you got to try. And in three days I was walking. So...very slowly and very carefully, but I was walking. And I couldn't swallow good, couldn't talk correctly, I blurred my words.

I You slurred your words?

S Very bad. But as time went on, it's been over three years now, as time went on I just--then one day about six weeks after I was home, one of my customers called me. I have a beauty shop here in the home--and said can you give me a permanent. Said, I'll help you. I said, you got the time I have nothing but time. And it took us twice as long but we got it done. And she called me and said that was the best perm that she ever had. So you just, you just have to try. And I was--I love to cook. And I have a son that comes by occasionally and wants--he loves fried okra, and I couldn't hold it and cut it. So I got a chopping block and just took a knife like this, you know, and just slid it across it. And I could do about half of it and I'd have to go lay down and get up and start over. But I'd start about noon to have supper ready at six (laughs) but I did. And I got on the first of May--well around the first of May and his birthday is the nineteenth. And I have never failed to make him a chocolate three layer cake. And I thought, oh how am I going to do it? But I made the cake. And I make them from scratch not mix. So I put all the ingredients on the table and mixed it up one day and baked and then I iced it the next day.

I So you found a way to do it?

S Uh huh (affirmative) I make jello and I couldn't get it from the sink to the refrigerator without spilling it. So I'd put the dish--you know I had put it in a big dish and put the dish in the refrigerator then going to pour it in the refrigerator, you know, in the dish. So there's several ways of doing things. Course I have a dishwasher but they suggested in therapy that I wash my dishes by hand to warm water on my bad hand

would help. And just leave them in the dish drained and let them dry at room temperature. And they teach you a lot of ways to save steps, you know.

I And how is it for you doing these things in new ways?

S Well I just adjusted to it and gotten used to it, and I didn't use my dishwasher for a year or so. And then I decided one day to use it and the water ran over and came out and I called a repairman. And he says it's because you haven't used it, the rubber's, it's, it's--well it's been dry too long, so you use it. And I did. And of course, my husband does the vacuuming, most of it, and the heavy work. But I went back to work full time.

I You did?

S Uh huh (affirmative) The first, first month I'd work--I took like two customers in the morning and two in the afternoon. And then while they were drying the 30 minute period it takes most ladies to dry, I would lie on the sofa and rest. I'd take one like at nine and then one at eleven and then have my lunch and rest and one at two and one at four. So eventually I got back, well I lost about half of my customers. I had about 25 when I had the stroke and had a whole book full--I had my stroke on Tuesday and I was to work Wednesday, Thursday and Friday, so they had to call and cancel. But I think my stroke was brought on by mental stress, due to the fact that my youngest son and his wife having trouble and she left him with two small children, age three and five. And we had to pitch in and help. And with my work and my age, and cooking dinner every night and tended to just two small children, it was just too much. So I suggested that we go to our church and talk to the minister and see if he couldn't get them in a day care center. Cause you don't just walk in there, you have a waiting list. And he told him, said we need some assistance with the children, not financially, that wasn't the problem. But he just went around in the day care and told them to make room for them. That was on Monday and I took them Monday morning and he picked them up Monday afternoon and I took them Tuesday and at five o'clock Tuesday I had a stroke. So the Lord works....

I It's hard for you to remember this.

S And they're fine now. They're with their mother. I don't know whether that's the best thing or not. But the judge said it was. I sometimes doubt it because, in my opinion, she's not as good a mother as she should be. But who am I to judge? But everyone in my family thinks that's why I had it. Because I'd been to my doctor that morning, had a complete physical, chest x-ray, the whole ball game, the whole thing. And she said I was in good health and at five or five thirty that afternoon I was cleaning off the dishes and making lunches for my son and I just, something burst in my head and I couldn't--I went over to the door and called my husband he came and helped me down the steps. He called

911 and they came and took me to the hospital.

I What were you aware of at the time?

S What was I what?

I What were you aware of at the time that you had the stroke?

S I really don't know. Just going the routine of washing up the dishes, cleaning up the kitchen, making a lunch, I make him a little plastic lunch, five a week, cause he works at the foundry and he's foreman and it's hard for him to leave and go out to eat without someone there to replace him. And I've been doing that since his wife left. So I just probably took on too much. But it was just like a bee sting, you know, in my head. I said something's wrong. But I didn't know what. And I thought well, maybe I took the wrong medicine. I'd just taken a couple of pills that I was supposed to take after I eat. And I went over to look at the bottles and then I couldn't see them. So that's when I called my husband. And he said "What's wrong with you?" And of course I couldn't talk at that point. I just motioned to help me. So he immediately called a neighbor over and she called 911. And I went to Red Bank and stayed a week and then they took me to ?? for three weeks. And the doctor said they usually keep a stroke patient four to six weeks. And I said is that compulsory? He said no you can go home today if you want to. But we'd like to help you. We'd like for you to give us an opportunity to help you. And I said well, I want to go home in three weeks. He said, we'll see. And every morning I'd say we--how many days I had left and he would smile and he was a wonderful doctor. And on the twenty first day I said you're not going to tell me I can't go home today are you? He said not this close to you (laughs). He said, you're the most--and he told my husband, he said "I've had lots of patients but she is really determined to get better and go home to you." But he was wonderful. So that's just about it isn't it? Can you think of anything else to ask me?

I Well I'm just--since you've had your stroke, any specific experiences--you've given me several, you mentioned before we turned the tape on about learning to write. Could you tell me a little more about how that was for you?

S Well, your whole hand is paralyzed and they give you a pencil with a round thing down over it, you know, so you can hold it. Cause I couldn't hold a pencil. And then you, you just practice writing. And the first I did was terrible, looked like a first grader, you know, or worse (laughs).

I And how was that for you, having to re-learn?

S Oooo, it was devastating, you know?

I It was devastating.

S I went to the bank and told them, that was my signature, if they didn't recognize it. And they said of course they'd honor my checks because I've banked with them for years. And uhh, sometimes I would get the person to fill them out and I would sign them. Cause writing was most difficult and after a while you'd get a cramp, you know. The muscles--at (names hospital) when the therapist would say pick up something and you couldn't. And I'd say I can't do it. They had machinery that they'd get and the only way I can express it in layman terms is like jump starting a battery in a car. They put the power to you, jumped the nerves, and then you could move them.

I That's a good analogy

S They really know what they're doing at (names hospital). They really are--sometimes you think they're not so kind, but they don't feed you. I lost 30 pounds in three weeks because I couldn't get my food to my mouth. But that's a way of making you do it. And you get hungry enough you get it there. And of course, I'm right handed. And this was paralyzed and my left hand I used. Of course, they put a bib on you and expect you to eat. So...

I And how did you experience that?

S Got it all over me for a day or two but...

I And how was that for you?

S Huh?

I How was that for you?

S Just like I said, it was just devastating. One day you're who I was, you know. You're in business and you're running a business and you're a grandmother and a wife and you drive, you go anywhere you want to, write a check, buy groceries or whatever. And the next day you're flat in bed, helpless. And they take all your jewelry away and they said, do you have a living will? And that gives you a great deal of anxiety. That's the first thing they asked me when I went in (names hospital). Do you want to be put on life support if necessary? I did not. And I told them so. And as soon as I got out I--the first thing my husband and I did was get a living will and bring our will up to date. And then when I got physically able we went to the funeral home and made all the arrangements.

Cause this is inevitable at our age. I'm 73 and he's 74. So you think a little bit more seriously. And I think there was a lot of prayers said for me. I've been a member of the Red Bank Baptist church since I was nine. And go regularly and my husband--and I've stopped counting my get well cards at 150. Flowers, they had three of these tables for my flowers, three. I even got them after I went to (names hospital), which, you know, people usually stop sending flowers. But I guess I made some friends. I used to work in PTA and was in everything that I could possibly do. And in my beauty shop I have senior citizens and I go get them and take them home, no charge, you know, just just because I want to.
I You've been really active in your community.

S Oh yes, yes, yes. I think it would be awful to lie in bed all day and not be missed, if you're not needed.

I It seems as though you were missed.

S Oh yes, yes--food and flowers. Yes And my husband, he's a good husband a good provider but he's not a man that does domestic things, he wasn't until I got sick. He said I don't even know how to turn the washing machine on. I said well you'll just have to learn. Because there's nobody else to do my clothes except my friends and I didn't want them to do that. So he learned quite a bit in a month. See he and my youngest son had the care of the grandchildren, the two men, for a whole month. They fed them, bathed them, took them to day care, picked them up. If he wouldn't get up early, get his shower and do his hair and get ready, my son would bring the children over here. He wanted them at night, and of course, their mother was gone and he'd bring them over here at ten after five in the morning and they'd go back to bed. And then he'd get them up about seven and after he'd gotten ready for work and cooked their breakfast, feed them cereal, bring them up here to get them dressed, take them to day care and then he'd go to work. Then my son would pick them up. You can do most anything that you want to do if you put your mind to it. I think. Don't you? By the help of the Lord.

I You've certainly put your mind to a lot of things and managed to accomplish a lot of things.

S Yeah, I, I do about three, maybe four customers in the morning now. Then I have my lunch and lie down and rest at least 30 minutes, sometimes an hour. And then I get up and do two or three more.

I This is different from before your stroke?

S Oh yeah. But I have to rest, I run out of steam. I just get exhausted quicker. But after all my age, most people don't work that late. But I don't want to quit. I mean it's

not for the money as much as the satisfaction that I can do it. Because I've never had to work. Because I've had a good living all my life. My husband's a very good provider. So I'm just grateful I'm still able to do. And I've had my granddaughter all week at night, this past week. She's with her daddy today. But they are divorced now. He gets them every other weekend but since school's out he gets them one at a time and we share them.

I How is it for you seeing her now?

S Beg pardon?

I How is it for you seeing her now, she's a little older I presume?

S The granddaughter?

I Yes

S She's six, will be seven July 14, and the other child is eight, the boy is eight.

I And how is it for you now when the grandchildren come over?

S Fine. They're old enough to help themselves. They learned very young to bathe and dress and brush their teeth and this sort of thing. And they, they help me when I had the stroke. (Granddaughter) would say come on I'll teach you how to walk. And she--I let her think she was helping me and she was, that you know, I had this supportive family. So I give a lot of credit to 911 because they got here just right away, put the oxygen on. See they tell me that the sooner that you get oxygen, you know, you've lost the flow of oxygen, you just pass out. I never did completely pass out but I couldn't respond. I couldn't talk, couldn't walk. And my husband said what's your doctor's number? And I went to look it up and I couldn't, couldn't, couldn't function. So he went next door. He ran next door and got the neighbor and she called 911 and they took me right away to the hospital. And then my children came. But anyway it's been quite an experience. A lot of prayers were said. But I do think we have to have the will to live. Now, I have a customer that had a stroke. And in my opinion it wasn't nearly as bad as mine and I say that because she wasn't paralyzed. She was more or less mental damage. But she just didn't want to do anything. She has a sitter come and fix her breakfast and her lunch and do her laundry and do her--the things that, if she would do I think she could. You just have to make yourself. Even when I came home on furlough. They let you come home after a short time, when they think you're able. And they insisted I bring the walker. I mean, the four prong cane. And I set it by the door when I got here and I picked it up on Sunday afternoon when I went back. I did not use it. Because to me, it would be harder to learn to use that, cause you have to move it out before you step. And I didn't want to get

dependent on it. And of course I came up these steps but I sat down and came up backwards. That's another thing you can do if you'll just figure out a way.

I You really have figured out a lot of ways haven't you?

S Yeah.

I What's bringing the tears to your eyes now?

S What?

I What's bringing the tears to your eyes now?

S Memories.

I Experiencing memories. Is it a sadness you're feeling?

S Well, I didn't think anything happens without a reason. And I guess I was just doing too much. And I needed to be slowed down. So that's all I can figure out because I was a healthy person. But a stroke is just something that happens. And I asked my doctor why didn't my doctor find this out? He said well that is very very possible that you can be fine at ten o'clock in the morning and have a stroke at five, five thirty in the afternoon, and not show up on any tests. See I even had x-rays that morning, complete physical, the same day I had the stroke. And she was, she was just devastated. Of course she came to the hospital but she had to call in specialists. But umm, I personally just think it was a lot of stress and I was trying to do too much. And I was worried. See, this son had had a motorcycle accident in 1990 and he only has the use of one hand and arm--well, he doesn't have the use of his left hand at all. He can use his arm to pick up something. So I feel like I help him, you know, because he has this disability. And I just worry about it. Although he's a grown man but I'm limited to what you can do with two small children to be left with you. But I just don't understand mothers that will leave children. Do you?

I It's hard to understand.

S Uh huh, yeah. Precious little children.

I Difficult for you. It sounds like it's been difficult for you understanding.

S Yeah, yeah--I don't really understand. I love mine so much nothing would take me away from them. But I had my children late in life. I was 28 and 30. And these children's

mother was very very young. There's 14 years difference in she and my son. And perhaps she just wanted some freedom, I don't know. But the judge saw fit to give them to her. And she moved out of town with them. And we get them every other weekend. Sometimes a week at a time, you know, when they're out of school. But that's just about all I can tell you. Kind of rough.

I It's been kind of rough?

S (pause) They tell me that it's characteristic of a stroke to cry. The emotions are damaged I guess, you know. Most stroke victims cry. The doctor said that's just normal. Of course, for two or three weeks I cried all the time (laughs). But uhh...

I How is it for you when you're crying?

S Well...

I What are you aware of or what are you feeling?

S You just kindly--like the busy person that I was, I was active in everything. And my husband I would go places, do things. He's a Shriner and we--we'd both--I belong to the ??? and he belongs to ??? and this. It's just difficult to, like I said, wake up and you're paralyzed. You can't even swallow your food properly. You eat pureed food. You don't know what it is but the color. If it's orange it's probably potatoes, sweet potatoes. It's baby food, you know, pureed. And like I said, your checkbook, your money, your car, your jewelry, everything but an old jogging suit and a pair of comfortable shoes is taken away from you. And you're stuck in a hospital with a lot of depressed looking people. And you go in to breakfast and they're sitting around, you know, depressing. And some of them had been in wrecks, with tubes in their nose and all this. It's not the atmosphere that you're used to. And you're one of them. That's, that's the bad part (starts to cry).

I That you're one of them.

S But when I came on furlough I washed a couple loads of clothes, folded them. The therapist said "you didn't." I said, yeah I did, you know (laughs). I wanted to. I'm going to just see what I could do.

I And how was it for you when you were able to do?

S Good. Good. Of course I'd get up and down very slowly and walk very slowly. But I said I was going to be able to walk out of (names hospital) and I could have. Of course they make you go in a wheelchair. But they wanted me to get a wheelchair and get

this and get that. And I said no. And wanted me to have home nurse care and all this. And I says I don't need it. I don't want it. So I did go, I think it was two weeks, twice a week to (hospital) for therapy, after I was released. But I could do everything they challenged me to do and when the therapist met with the doctor and said "what will I do with her, what shall I" he said well, I don't think she needs any more therapy. They had me put nuts and bolts together and work with your fingers and then they finally give you a pair of tweezers to pick up something and do with, that's most difficult. But they try to make it hard. So like I said, sometimes you think they're cruel. There's a reason. They have a little apartment out there and you go in and the therapist will tear all the cover off the bed. And say "now make it up." And of course I put the hospital fold on it and everything like I do--like I used to before they had fitted sheets, you know. Said "that's great." And they had me, they took me in one of their station wagons or vans to the grocery store and gave me ten dollars and said--you plan a menu and then you go in and buy what you need, then come back and cook it. And I did that. They want to see if you're mentally alert. See if you--the clerk's going to cheat you or you get the right change, want to see if you can function. And then my husband, I said I want to drive. They recommended me to take a driver's education and I said I don't need that, I just need time. Because I started driving when I was 13 years old and a four in the floor shift car, going up and down Signal Mountain with my dad. And that was devastating to think I had to take drivers license, driver's lessons. So I did not. So (husband) took me to the vacant lot at K-Mart. And at the time I had a van and he said now get under the wheel and take it around the building. And we did that several times until I got the feel of the car. He says "you're okay." But he's always been very encouraging even when the weather's bad, and we live on this hill, maybe I'll call him by ten o'clock if it's icy or snowy I ask him can I get off the hill? He said "well I did, you can." So he's very supportive. If I can go you can go. And he'll never tell me not to do anything. Cause I'm the sort of person if you tell me not do I go do it, just as a challenge.

I So he doesn't limit you?

S No, no. Very supportive. And since my stroke been much, much more attentive.

I More attentive?

S In other words, we come up for breakfast, he gets the milk, gets the cereal bowls, makes the toast and then puts all this away. When used to, I did it. But he does it. And it's nice to be pampered.

I So you appreciate his help?

S Very much, very much. I appreciate him. So, I don't know anything else I can tell

you except it just takes time and very definitely the will to live. Maybe the Lord wasn't ready for me to go. And so he let me get better.

I And you had the will to live.

S Uh huh, uh huh (affirmative) Cause I really thought that my time had come. I didn't think I'd ever be back in the beauty shop working. And that--like I say, just right now, you're driving and going and everything, if tomorrow this would happen to me. And it could, it could happen to anybody. So, in 1990, my son had the motorcycle accident. '92 my husband had three bypass heart surgery and '93 I had the stroke. And I continue to work. Now like I told you before, I do not have to work. But to me I have to work because I have customers and they're counting on me. And some of them I go get and take home. And it's not for the money it's for the, it's for the satisfaction of being able to do it. And of course my customers are all my friends. I've known them, some of them I've had ever since I've been working. And I lose one or two a year. Recently....

I To death?

S Huh?

I To death, you lose one or two...

S To death or moving closer to their children, moving out of town and going into retirement centers and getting their hair done there, at the retirement centers. But I'll lose on average of two or three a year. So that's okay, cause I couldn't do that many any way, you know. It balances out and it doesn't, doesn't cost me if I don't open the shop cause it's in the home. And I don't have to pay for a business phone or rent. So that's different that this job that's out in a mall or somewhere.

I What's it like for you when you lose your customers?

S Well, I can accept someone dying of old age, you know, if they've lived a good life. I even go to the funeral home and do their hair if they're my customer.

I Do you?

S Uh huh. First time it was awful hard. But I said, well somebody has to do it why not me. I know how they want it. And a lot of them request it. Say "when I die I want you to do my hair." So, it's just like whoever prepares them, they have to be done. (Phone rings) I think he'll answer that he knows you're here. There's a phone out back. Well have I helped you?

I Well you've shared a lot of experiences with me, yeah.

S I hope I have. Cause to me you need to be encouraged. If you want to do, just like the lady I told to push the wheels and it'll go. And she got to her room and she got better. And just don't holler hey you, do it yourself if you can. Because when I ask somebody to do something, I need them. Otherwise I do it myself. I never ask for help if I can do it.

I What about when you were in the hospital?

S Well, it's like I said, it's devastating for somebody to have to lift you up out of bed and put you in a wheelchair when you've been doing everything. And especially assist you with a bath, you know. It's just, I can do it, but you can't. Before you realize it you say I can do it but you can't.

I Are you all right?

S Oh I'm fine, I'm fine. I'm fine. I just, like I said, it brings back memories and it is sad. But with the help of the Lord I think I'm 90% rehabilitated. I can go up 32 stairs three or four times a day. I drive. I shop. You see, the other day I went and bought a large amount of groceries, bought us $102 worth. And my husband wasn't here, and I carried them all upstairs and put them away. And a friend says "how in the world did you carry those groceries?" I said, well, I took half of them out before I started up and I took the half of the bad and set it two steps up and then I came up two steps and emptied it out. And with the empty bag I've got the other side, the other bag. And I put them up. There is a way if you want to. Now some people let their groceries set there and if somebody comes along and carries it up for them. But if you can carry a can of beans, you can carry a can of beans, right?

I It's another example of your finding a way to do something.

S And another trick they tell you, when you change the linens, just wash them and put them back on. Then you don't have to bother folding them up. Just leave your bed unmade, put them back on the bed, you know. It's just a lot of ways you can cut corners. And you don't have to be--like I used to be, I would vacuum every other day or so and wash windows four or five times a year. But you can live and live very, be very clean, but you don't have to do that. You don't have to wash your sheets every five or six days. You can, you know, things can go. Of course, you don't want it to get dirty. But you don't have to do that quite as much if it means help.

I If it means health?

S Help. You have to take care of yourself. And the doctor told me when he released me. He said, the only thing--trouble I have, he's told my husband to let go, she may over do. And he never ??? and he said, you could come right back here if you're not careful and take care of yourself. And if you don't do it nobody else will do it, you have to do it. Just like the therapist told me I had to make an effort to walk. He couldn't pull me out of the chair and make me walk. He said, I'm here to help you and I've never dropped a patient yet. And he was like a big football player, you know, tall. And I went back to (hospital) to see a friend last week. And I went down to therapy and looked him up. And he came walking up there. And I said hi. And he said hi. And I said, do you remember me? He said, I do but I don't remember your name. And in a few minutes he called my name. And he was so glad to see me. Of course, he embraced me. And I was glad to see him.

I You were glad to see him. He really made a difference for you.

S Uh huh (affirmative) yeah, yeah he made a--he was the one I remember most because of what he said. And he was very kind but it was true. He said I can't make you walk but I can help you walk. You have to be motivated to want to do it and that has to come from you.

I And that really impressed you.

S It did. Wouldn't it you?

I Uh huh

S Yeah

I So when you were talking earlier about people having strokes needing encouragement that's the sort of encouragement that you're referring to?

S Yeah, I went up to (hospital) several times, particularly when I know a person, and I will go to room 318 and that was my home for three weeks. And I went in and there was a little lady laying in that bed. And I introduced myself. And I said, have you had a stroke? And she nodded her head because she couldn't talk. And her husband was sitting in a chair. And I said, well you may wonder who I am. But I said, that was my bed for three weeks and I got better. And I want you to do that too. And she smiled. And I don't know what the outcome of that was. I didn't follow up.

I But you were providing her with encouragement.

S And I went back and of course, when I was a patient there, like I said, you were in

jogging clothes, and no makeup and I couldn't do my hair properly. And being a beautician that was degrading. And uhh, one day I dressed up, went out there to visit someone. And I thought, well I'll go see my doctor. And I stood by there, and he looked up "may I help you?" And I said, don't you remember me? And of course, well and called my name. And said, gee you look great. And I said yes and I drove myself out here, by myself. And that, that (end of side one)....not necessarily doubtingly, he didn't want me to over do. He didn't want me to get in a car. In fact, when he left the room for the therapist to talk to me, he came back. And he said, promise me that you won't drive until such time that you're able. And my husband said, she'll be okay. I'll watch her. Just like I told you before. I've grown up--when everybody was poor, you do things, you make do. And I've always worked. And learned how to do things when you didn't have the proper things to do with. And you know, been a good provider for my children, cooked for them and all this. So I guess that's about all that I can tell you. I don't know of anything else. Do you?

I Is there anything else you'd like to add that you can think of?

S No.

I I really appreciate your taking this time with me and sharing these experiences.
S You're quite welcome.

VITA

Janet Alice Secrest was born in Victoria, British Columbia, Canada where she attended public schools. In 1969 she entered the Royal Jubilee Hospital School of Nursing, graduating in 1972 with a diploma. In 1984 she was awarded a Bachelor of Science in Nursing Degree from North Carolina Central University in Durham, North Carolina. In December of 1987, Janet received a Masters of Science in Nursing, Adult Health with a functional role in Administration, from the Medical College of Georgia, Augusta, Georgia.

Janet's nursing career has included working with hospitalized clients of all ages. For ten years, her practice was centered on those with neurological disorders. For the last few years, her focus has shifted to education where she has taught students in associate degree programs, and most recently, a baccalaureate program.

In August, 1993, she entered the doctoral program in nursing at the University of Tennessee, Knoxville and received her Doctor of Philosophy degree in August, 1997.